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IN THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF UTAH, CENTRAL DIVISION

STACI CHRISTENSEN, an individual; JOHN R. WEAKLY, an individual; AND DISABILITY LAW CENTER, a Utah nonprofit corporation,

Plaintiffs,

VS.

JOSEPH MINER, M.D., in his official capacity as Executive Director of the Utah Department of Health; NATHAN CHECKETTS, in his official capacity as Director of Utah Division of Medicaid and Health Financing; ANN WILLIAMSON, in her official capacity as Executive Director of Utah Department of Human Services; ANGIE PINNA, in her official capacity as Director of Utah Division of Services for People with Disabilities; UTAH DEPARTMENT OF HEALTH; UTAH DIVISION OF MEDICAID AND HEALTH FINANCING; UTAH DEPARTMENT OF HUMAN SERVICES; and UTAH DIVISION OF SERVICE FOR PEOPLE WITH DISABILITIES,

Defendants.

PROPOSED CLASS ACTION COMPLAINT FOR DECLARATORY AND INJUNCTIVE RELIEF

Case No. 2:18-cv-0037

Judge Dale A. Kimball

Plaintiffs Staci Christensen, John R. Weakly, and Plaintiff Disability Law Center (the "DLC"), each of whom appears individually and on behalf of others similarly situated, hereby complain of Defendants Utah Department of Health ("Health") and its Executive Director Joseph Miner; Utah Division of Medicaid and Health Financing ("Utah Medicaid") and its Director Nathan Checketts; Utah Department of Human Services ("Human Services") and its Executive Director Ann Williamson; Utah Division of Services for People with Disabilities and its Director Angie Pinna, and allege as follows:

I. <u>INTRODUCTION</u>

- 1. This case is about the unlawful institutionalization and segregation of men and women with intellectual or developmental disabilities in the State of Utah. The Individual Plaintiffs in this case live in private intermediate care facilities ("ICFs"), and are two of the approximately 600 people with disabilities who reside in Utah's private ICFs.
- 2. Utah's private ICFs are inpatient institutions that restrict the ability of their residents to lead fulfilling, self-directed lives. Most of them are large facilities, with up to 83 beds per facility. In most instances, individuals share a room with at least one other resident, and in some cases, up to 4 adults share one small room.
- 3. The Individual Plaintiffs, and many others like them, yearn to receive services from the State of Utah that will free them from an institution that lacks privacy, fails to support fulfilling connections to their communities, which relegates them to lives of segregation.
- 4. However, the State of Utah operates its service delivery system for individuals with intellectual or developmental disabilities in a manner that denies the Individual Plaintiffs meaningful opportunities for integration into their communities, and unnecessarily segregates people who live in private ICFs. By relegating the Individual Plaintiffs to a life of segregation, the State of Utah violates federal law requiring it to provide integrated services to all individuals who do not oppose placement in a community setting and whose needs can be accommodated in that setting. Utah does not provide an effective mechanism for leaving a private ICF and, without a change in the way Utah administers the programs and services at issue herein, many residents will remain in this life, segregated indefinitely.

- 5. Over eighteen years ago, the U.S. Supreme Court held that unnecessary institutionalization of individuals with disabilities is unlawful discrimination under Title II of the Americans with Disabilities Act in *Olmstead v. L.C.*, 527 U.S. 581, 597-600 (1999). Since the *Olmstead* decision, many states have responded by reducing their reliance on private ICFs for individuals with intellectual and/or developmental disabilities and increasing their use of community-based services and supports.
- 6. In contrast, no meaningful progress toward integration has been made for Utahns segregated in private ICFs. Contrary to national trends, Utah is increasing its reliance on institutional care for individuals with intellectual or developmental disabilities in the State. There are currently 18 licensed private ICFs scattered throughout Utah, almost all of which are large facilities with 16 or more beds. In the last 5 years, Utah Medicaid has approved at least four additional facilities for a total of 71 additional beds (a 13 percent increase), and is poised to add many more.
- 7. Utah's private ICFs are licensed and administered by Health. Health functions separately and apart from the Division of Services for People with Disabilities, Utah's agency that holds the requisite knowledge and responsibility for providing services to the vast majority of individuals with intellectual and/or developmental disabilities receiving services within the state of Utah.
- 8. Individuals who are served by Health in private ICFs are excluded from the larger service system despite having no discernable difference in diagnosis or scope of need than those individuals being served by the Division of Services for People with Disabilities.

- 9. The State already offers an array of community-based services for people with intellectual and/or developmental disabilities, including residential services, which are overseen by the Division of Services for People with Disabilities. However, the Individual Plaintiffs are systematically denied access to these services. The State's administration of the developmental disabilities service system prevents individuals living in private ICFs from accessing home and community-based services in the same manner as individuals with an intellectual or developmental disability who are not living in a private ICF.
- 10. Individuals, including the Individual Plaintiffs, who reside in private ICFS are denied access to community-based services because they cannot meaningfully utilize the only two mechanisms available for an individual with an intellectual or developmental disability in Utah to receive community-based services.
- 11. The first mechanism is the waitlist for community services, which is operated by the Division of Services for People with Disabilities. Residents in private ICFs are given a low priority ranking on the waitlist and have virtually no chance of getting off that list, which forces them to use the second mechanism, only available to individuals living in private ICFs, known as the Transition program.
- 12. The Transition program does not provide individuals in private ICFs meaningful access to community services because, among other reasons, it operates in an arbitrary manner that does not guarantee funding in any given year, it fails to adequately inform individuals of the program's availability, and it does not function to deinstitutionalize members of the Class. As a result, individuals who reside in private ICFs are effectively locked out of both pathways to community-based services.

- 13. Collectively these actions and inactions violate Title II of the Americans with Disabilities Act ("ADA"), ADA, 42 U.S.C. § 12131 *et seq.*, Section 504 of the Rehabilitation Act, 29 U.S.C § 794 *et seq.* ("Rehabilitation Act"), and the United States Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). The State's actions are discriminatory because the Plaintiffs suffer segregation and discrimination as a consequence of living in private ICFs.
- 14. Plaintiffs bring this lawsuit on behalf of themselves and all members of the class of persons with intellectual and/or developmental disabilities who are eligible for Medicaid, who reside in private ICFs in Utah, and who would not oppose living in a community-based setting.

II. <u>JURISDICTION AND VENUE</u>

- 15. This action is brought pursuant to Title II of the ADA, 42 U.S.C. § 12132 *et seq.*, and the Rehabilitation Act, 29 U.S.C. § 794. This Court has subject matter jurisdiction pursuant to 28 U.S.C. §§ 1331 and 1343 because this action concerns claims arising under federal law.
- 16. Plaintiffs' claims asserted herein arose in Utah and Defendants are Utah state agencies and agents.
- 17. The Court may grant the relief sought by Plaintiffs pursuant to 28 U.S.C. § 2201-2202, 42 U.S.C. § 12133, 29 U.S.C. § 794a, and Rules 57 and 65 of the Federal Rules of Civil Procedure.
- 18. Venue in this judicial district is proper under 28 U.S.C. §§1391(b)(1)-(b)(2) in that this is the judicial district in which Defendants reside and this is the judicial district in which a substantial part of the events and/or omissions at issue occurred.

III. PARTIES

A. Plaintiffs

1. Staci Christensen

- 19. Ms. Christensen is a charismatic young woman who wants to be an active participant in her community. Although Ms. Christensen is only 29 years old, she has already spent 9 years—nearly her entire adult life—in private ICFs. Ms. Christensen is eligible for Medicaid, and qualifies for ICF services because she has Down syndrome, a type of intellectual disability.
- 20. Ms. Christensen has a strong desire to live in a community-based setting. With appropriate services and supports, Ms. Christensen could live in the community.
- 21. Ms. Christensen lived with her father until she was a young adult, but moved to a private ICF after he remarried. For several years, Ms. Christensen lived at a 50-plus bed facility where she had as many as three roommates at one time.
- 22. The large ICF's chaotic setting was uncomfortable and upsetting to Ms. Christensen, who began looking for ways to leave the facility. Ms. Christensen has tried several times to move into a community-based setting, but Health made no such services available. While Ms. Christensen was unable to transfer to community-based services, she was able to move to a smaller private ICF.
- 23. Ms. Christensen works at a sheltered workshop for people with intellectual disabilities. Ms. Christensen attends the workshop 3 days per week and performs tasks such as sorting items and recycling discarded materials for subminimum wage.

- 24. Ms. Christensen has long wanted to find a more integrated job in the community, and has past work experience in community settings. For example, Ms. Christensen previously worked at a local university as a dishwasher where she was part of a small work crew that cleaned and dried dishes.
- 25. In an effort to find community-based employment, and without any assistance from the staff at her private ICF, Ms. Christensen applied for, interviewed, and was hired for a job at a local restaurant located approximately an hour away by public transit from her ICF. Ms. Christensen uses public transportation to navigate to and from work, and has been successfully bussing tables and acting as a hostess for the last 2 years.
- 26. Because Ms. Christensen's shift at the restaurant is approximately 10 hours of work per week, she still spends the majority of her time during the week at the sheltered workshop. Sheltered workshop staff acknowledge that Ms. Christensen is not able to benefit from their vocational services, yet she is required by her private ICF to continue working there for a majority of her days.
- 27. Ms. Christensen enjoys spending time with her brother and sister, and her grandmother and she would like to live closer to her grandmother.
- 28. Despite her living situation, Ms. Christensen tries to be an active participant in her community and is a passionate advocate for other individuals with disabilities.
- 29. Ms. Christensen is capable of living and working in the community with appropriate services and supports. However, the Defendants' administration, planning, and funding of the service system for people with intellectual disabilities has denied Ms. Christensen

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the opportunity to live outside a crowded, restrictive institution, and continues to subject her to discriminatory segregation.

2. John R. Weakly

- 30. John R. Weakly is an outgoing 36-year-old man who resides in a private ICF with over 50 beds. Mr. Weakly is eligible for Medicaid, and qualifies for ICF services because he has cerebral palsy (a developmental disability), as well as spastic quadriplegia and a seizure disorder.
- 31. Mr. Weakly has a strong desire to live in a community-based setting. With appropriate services and supports, Mr. Weakly could live in the community. Unfortunately, Mr. Weakly has lived in various private ICFs for almost 14 years.
- 32. Mr. Weakly lived with his paternal grandparents until he was 16 years of age and they could no longer serve as his primary caregivers. At that time, Mr. Weakly moved in with his father until he could also no longer be a primary caregiver. Because he could not secure home and community-based services, Mr. Weakly's father moved him into a 50-plus bed private ICF in Salt Lake County. He transferred to his current private ICF approximately 18 months later.
- 33. At his current ICF, Mr. Weakly has a very small bedroom that he shares with 3 other men with developmental disabilities. Mr. Weakly uses a power wheelchair, which is difficult to maneuver in such a tight space. In addition, Mr. Weakly requires assistance changing his incontinence briefs; due to low staffing ratios at the ICF, he is often left waiting in soiled briefs for long periods of time.
- 34. Mr. Weakly has little freedom to determine the schedule of his day and ICF staff control his ability to participate in activities. Mr. Weakly enjoys technology, particularly Apple products. While Mr. Weakly makes occasional trips to the Apple Store in a nearby shopping mall,

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he must do so on his own and without any support from the ICF. ICF staff have instead prohibited Mr. Weakly from leaving on several occasions.

- 35. Mr. Weakly has also expressed an interest in having a romantic relationship, but ICF staff have instructed him he is not allowed to develop a relationship with a significant other.
- 36. During his day Mr. Weakly works at a segregated sheltered workshop where he works on recycling projects. Previously he worked in the community as a greeter for Toys-R-Us for two years. Mr. Weakly would also like to work in a more integrated setting, specifically working for the Apple Store. Mr. Weakly was able to obtain some employment-related services from Vocational Rehabilitation with the assistance of the DLC, despite ICF staff failing to provide assistance to do so and at times even preventing Mr. Weakly from communicating with Vocational Rehabilitation.
- 37. On information and belief, in the summer of 2017, Mr. Weakly was offered an opportunity to move into the community; however, ICF staff discouraged him from accepting the opportunity and gave him inaccurate information about living in a community-based setting. For example, the ICF staff told Mr. Weakly that he would have to pay his own rent, but neglected to also tell him that this would be paid with funds that were already available to him. ICF staff also told Mr. Weakly, incorrectly, that he would not be able to visit his friends in the ICF once he moved into the community. However, when Mr. Weakly was provided accurate information, he again strongly reaffirmed that he would like to move into the community.
- 38. Mr. Weakly is qualified for and could live in the community with appropriate services and supports. However, the Defendants' administration, planning, and funding of the service system for people with intellectual disabilities has denied Mr. Weakly the opportunity to

live outside a crowded, restrictive institution, and continues to subject him to discriminatory segregation.

3. The Disability Law Center

- 39. Plaintiff DLC is a non-profit corporation, and has been designated by the Governor of the State of Utah as the state's protection and advocacy "("P&A") system. The DLC is a federally authorized and funded organization established under the Protection and Advocacy for Individuals with Developmental Disabilities Act ("PADD"), 42 U.S.C. §15041, et seq. Under the leadership of its governing board, the DLC advocates for and protects the legal rights of people with disabilities, including individuals with developmental disabilities, across the state of Utah. The DLC consults with individuals with disabilities and their family members in identifying organizational priorities. The DLC accomplishes this by reserving space on its governing board for such individuals, providing a formal grievance process, and ensuring opportunities for public comment.
- 40. As the designated P&A system for the state of Utah, the DLC is authorized by Congress to "pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of [individuals with developmental disabilities] within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements." 42 U.S.C. § 15043(a)(2)(A)(i).
- 41. The DLC's 16-member elected governing board is knowledgeable of the needs of individuals with developmental disabilities. The governing board is composed of family members of people with developmental disabilities, attorneys, advocates, and other interested

and knowledgeable persons from the community. The DLC is closely connected to the interests of those it serves.

42. The DLC joins this action as an entity that has suffered and continues to suffer a distinct economic injury as it expends significant personnel time and financial resources to advocate for the rights of individuals who reside in ICFs to access community-based services. Additionally, the DLC represents its constituents, individuals with intellectual disabilities, who reside in private ICFs and who cannot receive integrated or community-based services due to Defendants' discriminatory service system.

B. Defendants

1. Utah Department of Health

- 43. Defendant Health is tasked with administering federally assisted state programs. Utah Code Ann. § 26-1-18. Health is Utah's single state Medicaid agency, responsible under 42 U.S.C. § 1396a(a)(5) and Utah Admin. Code r. 414-1-3 for administration of Utah's Medicaid program, a federally funded program.
- 44. Under Medicaid, the federal government provides partial funding to the states (in Utah, roughly 70% is federally funded) for the cost of medical and other services provided to eligible persons, such as individuals with disabilities. Services can include long-term services and supports to people with intellectual and/or developmental disabilities who reside in private ICFs or, under various waiver programs, receive services in the community. Utah Admin. Code r. 414-1-6(u).
- 45. Health administers the Transition Program, including determining whether sufficient funds exist to move individuals out of ICFs in a given year, informing ICFs and residents

about the program, and selecting individuals who will participate in the program. *See* Utah Admin. Code r. 414-510-1 *et seq*. In addition, Defendant Health is the state agency that administers the Community Supports Waiver for Individuals with Intellectual Disabilities and Other Related Conditions. *Id.* at r. 414-61-1 *et seq*.

2. Joseph Miner, M.D., Executive Director, Utah Department of Health

- 46. Defendant Joseph Miner, M.D., is the Executive Director of Health. He is responsible for overseeing the operation of Health and the Divisions within. Utah Code Ann. § 26-1-13. He also oversees, and aids in the appointment of, Division Directors, including the Director of Defendant Utah Division of Medicaid and Health Financing. *Id.* at § 26-1-14.
- 47. In addition, Defendant Miner is responsible for preparing and submitting an annual budget to the Governor for inclusion in the Governor's budget. *Id.* at §§ 26-1-13, 22.
 - 48. Defendant Miner is sued in his official capacity.

3. Utah Division of Medicaid and Health Financing

49. Defendant Utah Medicaid, a division of Health, is responsible for the implementation, organization, and maintenance of the Medicaid program in Utah. Utah Code Ann. § 26-18-2.1.

4. Nathan Checketts, Director, Utah Division of Medicaid and Health Financing

- 50. Defendant Nathan Checketts, as Director of Utah Medicaid, prepares and administers the budget for the Division, and is responsible for ensuring the Medicaid state plan complies with federal laws and regulations. Utah Code Ann. § 26-18-2.2.
 - 51. Defendant Checketts is sued in his official capacity.

5. Utah Department of Human Services

52. Defendant Human Services is the social services authority of the State of Utah, and is tasked with, among other things, promoting and developing a system of care for people with disabilities in Utah. Utah Code Ann. §§ 62A-1-111(22), 114(1).

6. Ann Williamson, Executive Director, Utah Department of Human Services

- 53. Defendant Ann Williamson, as Executive Director of Human Services, has administrative jurisdiction over each division within her Department, including the Division of Services for People with Disabilities, and is required to administer the office in compliance with state and federal law. Utah Code Ann. § 62A-1-110.
- 54. In addition, Defendant Williamson is responsible for preparing and submitting an annual budget to the Governor for inclusion in the Governor's budget. Utah Code Ann. §§ 62A-1-108, 113.
 - 55. Defendant Williamson is sued in her official capacity.

7. Utah Division of Services for People with Disabilities

- 56. Defendant Utah Division of Services for People with Disabilities is required to "ensure that the services and support that the division provides to any person with a disability ... are provided in the least restrictive and most enabling environment," and to help people with disabilities make choices for services and support that meet their individual needs and "promote independence, productivity, and integration in community life." Utah Code Ann. § 62A-5-102(6).
- 57. The Division is also responsible for making rules "governing the admission, transfer, and discharge of a person with a disability" from an ICF. Utah Code Ann. § 62A-5-103(2)(r).

58. In addition, the Division is the state agency that operates the Community Supports Waiver, a federally funded Medicaid program, for Individuals with Intellectual Disabilities and Other Related Conditions. Utah Admin. Code r. 414-61-1 *et seq*.

8. Angella Pinna, Director, Utah Division of Services for People with Disabilities

- 59. Defendant Angella Pinna, as Director of the Division of Services for People with Disabilities, is the head administrator for the Division and is required to administer the office in compliance with state and federal law. Utah Code Ann. § 62A-5-104(3).
 - 60. Defendant Pinna is sued in her official capacity.

IV. CLASS ACTION ALLEGATIONS

- 61. Plaintiffs bring this action as a class action pursuant to Rules 23(a) and 23(b)(2) of the Federal Rules of Civil Procedure, on behalf of themselves and all members of the class of Utah Medicaid eligible individuals with intellectual and/or developmental disabilities who reside in private ICFs in Utah and would not oppose living in a community-based setting (the "Class").
- 62. The individual Plaintiffs and the Class (collectively, the "Plaintiff Class") are entitled to be served in the most integrated, least restrictive settings appropriate for their individual needs. However, they do not have access to the integrated community-based services required to avoid their unnecessary institutionalization, and they are denied the opportunity to make meaningful and informed choices regarding alternatives to segregation.

A. Rule 23(a) Requirements

1. Numerosity

- 63. The exact number of residents of private ICFs who do not oppose living in community-based settings is not known to Plaintiffs with certainty, although the total number of private ICF residents is nearly 600.
- 64. The Defendants' failure to adequately assess individuals living in private ICFs to determine whether they oppose placement hinders Plaintiffs' ability to pinpoint the number. At a minimum, the number of existing Class members would consist of at least 70, as that is the number of individuals living in private ICFs who applied for the Transition program in 2015.
- 65. Utah's private ICFs are distributed throughout the State, from Odgen to Parowan, and as a result the potential class members are also geographically dispersed throughout the State.

2. Commonality

- 66. Common questions of law and fact that are capable of class-wide resolution exist as to all members of the Class. These common legal and factual questions include:
 - a. Whether Defendants are violating the ADA and the Rehabilitation Act by administering, funding and operating their service system for people with intellectual and/or developmental disabilities in a way that discriminates against the Plaintiff Class;
 - b. Whether the Defendants are violating the ADA and the Rehabilitation Act by failing to serve members of the Plaintiff Class in the most integrated setting appropriate to their needs;
 - c. Whether Defendants' service system for people with intellectual and/or developmental disabilities fails to accommodate the needs of the Plaintiff Class

- by investing in and sustaining the growth of segregated service settings, and by not providing them access to the Community Supports Waiver;
- d. Whether the Transition program violates the ADA by failing to provide the Plaintiff Class adequate access to integrated community-based settings, causing their unnecessary and unlawful segregation;
- e. Whether Defendants' service system for individuals with intellectual and/or developmental disabilities violates the ADA because it is designed to keep private ICFs fully populated;
- f. Whether Defendants' failure to provide sufficient information and support to the Plaintiff Class about community-based services and community living to enable the class members to make an informed choice leads to their unnecessary and unlawful segregation.

3. Typicality

- 67. The individual Plaintiffs' claims are typical of the claims of all members of the Class because each of the individual Plaintiffs and other class members are individuals with intellectual and/or developmental disabilities who qualify for Medicaid and reside in private ICFs in Utah. As a result, all of the Plaintiffs are subject to, governed by, and harmed by the same policies and procedures of the State.
- 68. For example, as alleged in more detail herein, both of the individual Plaintiffs are subject to the same rules that preclude them from accessing community-based services from Utah's Medicaid waiver through the waiting list. In addition, the only other mechanism available to them for those services is Health's Transition program.

69. Plaintiffs and all members of the Class have similarly suffered the same harm arising from Defendants' actions and inaction, namely, unlawful segregation and institutionalization, and they all possess the same interests because they do not oppose community placement.

4. Adequacy of Representation

- 70. The individual Plaintiffs will fully and vigorously prosecute this action, and can adequately and fairly represent the interests of the Class.
- 71. The Plaintiff Class is represented by attorneys experienced in federal class action and disability law.

B. Rule 23(b)(2) Requirements

- 72. This suit may be maintained as a class action pursuant to Rules 23(a) and 23(b)(2), of the Federal Rules of Civil Procedure, because Plaintiffs and other members of the Class seek declaratory and injunctive relief, and all of the above factors of numerosity, commonality, typicality, and adequacy are present.
- 73. Based on their common injury, Plaintiffs seek class-wide declaratory and injunctive relief pursuant to Rule 23(b)(2), in order to remedy and prevent their unnecessary institutionalization in ICFs and to provide them an opportunity to choose to live in the community.
- 74. A single injunction can cure systemic deficiencies by providing meaningful access to the Community Supports Waiver, which provides a range of services that can meet the needs of the Plaintiffs and members of the Class.
- 75. A class action is the best available method for adjudication of these legal issues because the State of Utah has acted or refused to act on grounds that apply generally to the Class,

and final injunctive relief or corresponding declaratory relief would be appropriate for the Class as a whole.

V. APPLICABLE STATUTORY PROVISIONS

A. The Americans with Disabilities Act

- 76. The ADA was enacted in 1990 "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities[.]" 42 U.S.C. § 12101(b)(1). In enacting the ADA, Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem[.]" 42 U.S.C. § 12101(a)(2).
- 77. In addition, Congress recognized that "people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally; [and] the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals[.]" 42 U.S.C. § 12101(a)(6)-(7).
- 78. Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. It applies to public entities, including state or local governments and any departments, agencies, or other instrumentalities of state or local governments such as the Defendants identified herein. 42 U.S.C. §§ 12131, 12132.

- 79. Title II's implementing regulations prohibit public entities, including Defendants, from utilizing "criteria or methods of administration" that "have the effect of subjecting qualified individuals with disabilities to discrimination," or "[t]hat have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities[.]" 28 C.F.R. § 35.130(b)(3)(i), (ii).
- 80. The "integration mandate" of Title II requires Defendants to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). This includes services under Medicaid. "The most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. § Pt. 35, App. B.
- 81. In *Olmstead v. L.C.*, 527 U.S. 581, 597-600 (1999), the U.S. Supreme Court held that Title II of the ADA prohibits the unjustified institutionalization of individuals with disabilities, and noted that segregation of people with disabilities "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, [and] economic independence."

B. Section 504 of the Rehabilitation Act of 1973

- 82. The Rehabilitation Act prohibits discrimination against people with disabilities under any program or activity that receives federal financial assistance, such as Medicaid. 29 U.S.C. § 794(a).
- 83. The Rehabilitation Act's implementing regulations prohibit recipients of federal funding from using "criteria or methods of administration" that have the effect of subjecting

qualified persons with disabilities to discrimination on the basis of disability, or that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program with respect to persons with disabilities. 28 C.F.R. § 41.51(b)(3)(i)-(ii); 45 C.F.R. § 84.4(b)(4)(i)-(ii).

84. These implementing regulations also require entities receiving federal funding to "administer programs and activities in the most integrated setting appropriate to the needs of qualified . . . persons [with disabilities]." 28 C.F.R. § 41.51(d); see also, 45 C.F.R. § 84.4(b)(2).

VI. GENERAL ALLEGATIONS

- A. <u>Long-term Care Services for Individuals with Intellectual Disabilities and/or</u>
 Developmental Disabilities
- 85. Individuals with intellectual and/or developmental disabilities who have long-term care needs and who meet the financial requirements of Medicaid are eligible to receive long-term services and supports through the State of Utah.
- 86. These services are mainly provided through Medicaid, a program that is jointly funded by states and the federal government. Medicaid provides health coverage to low-income individuals including people with disabilities pursuant to Title XIX of the Social Security Act, 42 U.S.C. §1396 *et seq*.
- 87. The federal government's share of Utah's Medicaid expenditures is approximately 70 percent. For every dollar Utah spends on Medicaid it receives 70 cents in federal reimbursement.
- 88. ICFs are institutions for individuals with intellectual disabilities and related conditions. ICFs are a covered service under Utah's state Medicaid plan. The State and Medicaid reimburse ICFs that deliver habilitative services as required by 42 U.S.C. § 1396d(d).

- 89. Health provides the majority of ICF services through privately owned and operated institutions. Health oversees the operation of private ICFs by licensing and contracting with these institutions and setting reimbursement rates.
- 90. Each ICF is reimbursed based on a daily rate. The daily rate, which is calculated by Health, varies between private ICFs and is based on a formula that is impacted by a facility's fair rental value. For example, Lindon Care and Training Center receives \$181.66 a day for each resident in their care while West Side Center receives \$186.44 a day for each resident in their care. Although rates may vary between private ICFs, the daily rates are fixed for individuals living in a particular ICF. Lindon Care and Training Center will receive \$181.66 per resident, regardless of the individual's support needs or medical needs. As a result, an individual living in a private ICF does not have a budget that is tailored to their individualized needs.
- 91. As an alternative to institutional care, Health also provides home and community-based care to individuals with intellectual and/or developmental disabilities through the Medicaid Waiver Program. The Medicaid Waiver Program allows states to waive certain Medicaid program requirements in order to serve individuals with long-term care needs at home and in their communities.
- 92. Utah's Medicaid Waiver Program for individuals with intellectual disabilities and related conditions is called the Community Supports Waiver, which provides medical and non-medical services, including residential care, for qualified individuals. The reimbursement rates for individuals served under the Community Supports Waiver vary depending on the particular needs of each individual, which will be appropriately reflected in their individualized budget.

- 93. Utah's Community Supports Waiver serves a fixed number of individuals and the maximum number of unduplicated participants who may be served in a given year is currently 4,650. The Division of Services for People with Disabilities maintains a waiting list for the Community Supports Waiver because there are more individuals who would like to receive waiver services than there are available slots. Individuals are selected from the waiting list based on an assessed needs score that ranks individuals by their critical need.
- 94. To be eligible for the Community Supports Waiver an individual must meet the ICF level of care criteria as outlined in Utah Admin. Code r. 414-502-8. The Community Supports Waiver supports individuals, who would otherwise be institutionalized, to live in their own home or apartment, develop meaningful relationships with community members, and make choices about how and with whom they want to spend their time.
- 95. The average wait time an individual spends on the waiting list for the Community Supports Waiver is approximately 6.25 years. For individuals who cannot remain on the waiver waiting list because they need services immediately, the only available option is to seek services in a private ICF.
- 96. Once an individual enters a private ICF they can remain on the Community Supports Waiver waiting list. However, because they are already receiving services in a private ICF, these individuals are not considered to have a critical need. As a result, state officials have acknowledged that an individual residing in a private ICF will not be assessed with a high enough needs score to transition to the Community Supports Waiver. Consequently, individuals residing in private ICFs are effectively denied access to the Community Supports Waiver through the traditional means of being placed on the waiver waiting list.

1. Utah's Growing Institutionalized Population

- 97. In Utah there are 18 private ICFs ranging in size from 8 beds to 83 beds. Over the past ten years, these ICFs have remained at or above 90 percent capacity with a yearly average of 94 percent capacity.
- 98. A private ICF with 16 or more beds is considered a large facility. Of the 18 private ICFs in Utah, there are 15 large facilities with 16 or more beds. Of the large facilities there are 6 that house more than 50 individuals. To the extent other that states still utilize ICFs, smaller models of 4 beds or fewer are preferred because it is widely accepted that quality of life indicators increase when people live in smaller settings. Currently, Utah does not have a private ICF that would qualify as a small facility.
- 99. Nationally, a majority of states have reduced their institutionalized population and have also reduced total number of private ICFs, since the *Olmstead* decision.
- 100. Defying national trends, Utah has instead chosen to grow its institutionalized population. For example, Health has licensed 5 new private ICFs since 2004, adding at least 71 beds to the service system and increasing the State's private ICF capacity from 580 beds to 651 beds—a 13 percent increase. Health is reportedly currently reviewing requests to add 3 additional 16-bed facilities, which would increase the private ICF population by yet another 48 individuals.

2. Utah's Private ICFs are Institutions

101. Private ICFs in Utah are segregated, institutional facilities. 42 U.S.C. § 1396d(d). They are neither home-like nor easily accessible by the community. They are typically locked, crowded, and generally have few staff available to assist individuals. Private ICFs are also

physically segregated from their community either by their location or by a locked gate that surrounds the building.

- 102. Due to low staffing, individuals are generally congregated around the front door or a television without interaction or support. Some individuals lack basic assistance for things such as toileting and medication administration.
- 103. In a majority of Utah's private ICFs, individuals must share a room with other residents and it is not uncommon for as many as 4 individuals to live in a small bedroom with roommates they did not choose or know prior to sharing a room. The few personal items individuals are allowed to have are often confined to the area surrounding a twin bed. The close living conditions afford individuals very little privacy in their day-to-day lives, which makes it difficult to make a personal phone call, safely store personal items, or find any time alone.
- 104. Individuals who live in private ICFs are subject to highly regimented schedules and policies that restrict their daily life. Medications are dispensed at scheduled times in a highly public manner. Meals are pre-selected and served in large, crowded dining areas. When individuals are allowed to go into the community, it is at specified times controlled by the private ICF. Rarely does an individual have the opportunity to choose an outing and go on their own with staff support.
- 105. Due to the segregated nature of private ICFs, residents are isolated from the broader community. Visitors are rarely present and many of the available activities are only provided onsite. Offsite activities are typically group activities with little opportunity for individuals to interact with their non-disabled peers. Individuals who wish to go into the community on their

own rarely receive transportation assistance and must navigate the public transit system without support.

- 106. Living in a restrictive, segregated environment inflicts harms on the individuals who live in private ICFs. For example, once an individual is placed in a private ICF they are often isolated from their friends and family. It is well established that social isolation has a profound impact on residents of private ICFs and leads them to engage in self-harm and feel they are unworthy of living in the community.
- 107. In contrast, home and community-based waiver services provide individuals with the support necessary to make fundamental choices about how they live their lives, including the ability to interact with non-disabled peers and otherwise go into the community.
- 108. Under federal regulations, home and community-based settings—including residential services—should be integrated in and provide full access to the community. These regulations also seek to ensure that if an individual is receiving home and community-based services, their life does not look materially different from anyone else's.
- 109. Residential settings are generally located in a neighborhood among other homes, churches, and local business. Unlike private ICFs, residential settings are not locked or gated, and individuals can choose to talk and socialize with their neighbors and friends at any time.
- 110. Home and community-based waiver services give individuals the opportunity to live at home with family, in an apartment, or in a small home with roommates of their choosing. The homes are decorated with personal photos, artwork, and other décor chosen by residents. Individuals generally live in their own bedroom decorated to their taste. In homes that have shared rooms, individuals choose their roommate instead of being assigned one. Because residential

settings are homes like anyone else's, they are much smaller than private ICFs with typically only 4-6 individuals living in a home.

111. Staff often assist individuals with their daily living activities, such as helping someone to paint their nails, cook their own meals, or choose an activity for the evening. Individuals in home and community-based services can choose their own meal times, when they wish to have visitors, and when they want to come and go.

B. <u>Utah's Administration of its Long-Term Care Services in Private ICFs</u>

- 1. The History of Utah's Efforts to Provide Access to Community-based Services for Individuals Residing in Private ICFs
- 112. In 1998, Utah acknowledged that the State's operation of the private ICF service system was vulnerable to lawsuits because individuals residing in private ICFs were unable to move from an ICF to a home and community-based setting. The State also recognized that the Department of Justice's interpretation of the ADA required the State to provide services for these individuals in a more integrated setting.
- 113. In response to this concern, Utah Medicaid and the Division of Services for People with Disabilities convened a task force to develop a plan that would allow for individuals to have a choice of settings. The taskforce's final recommendation was a mechanism called "portability."
- 114. Under portability, individuals were allowed to transfer their funding from a private ICF to a home and community-based setting and conversely from a home and community-based setting to a private ICF. The program was at first believed to be cost neutral because it assumed that a near equal number of individuals would choose to transfer from home and community-based services into private ICFs as would choose to transfer out of private ICFs and into home and community-based services.

- 115. From 2000 to 2002, there was tremendous interest in the program from individuals living in private ICFs who desired to live in a community-based setting. Because of this interest, the State transferred approximately 70 individuals from private ICFs to home and community-based services.
- 116. During this same time period, contrary to the State's assumptions, there were no requests to transfer from home and community-based services into private ICFs. Consequently, the program was not cost neutral. The State responded by placing a moratorium on portability for 2 years, effectively shutting off all access to home and community-based services for all individuals living in private ICFs.
- 117. In 2002, the State also began to restrict access to the Community Supports Waiver waiting list for individuals residing in private ICFs. In response to a 2001 audit of the Division of Services for People with Disabilities, the Division removed 135 individuals residing in ICFs from the waiting list based on the assumption that these individuals were already receiving care and could seek community placement through the portability program if they chose to do so.
- ICF population. Also in 2005, Health officials testified that the State's private ICFs were at or over capacity and suggested that portability should now be used as a mechanism to manage growth to the private ICF service system by transitioning a small number of individuals into home and community-based services so that additional private ICF beds could be occupied by incoming residents.
- 119. The program had effectively changed from one that provided individuals in private ICFs with the opportunity to live in a more integrated setting, to a program that moves only a

nominal number of individuals living in private ICFs into the community while ensuring that private ICFs remain fully populated.

- 120. Health made additional changes to portability at that time, such as allowing for a transfer of funds only from the private ICF service system to the home and community-based service system and by reducing the amount of information concerning home and community-based services available to individuals living in private ICFs. The impact of the changes implemented by Health was to restrict further an individual's ability to move from a private ICF to a community setting.
- 121. As currently codified, the portability program is now referred to as "Transition." To date, the Transition program has no dedicated funding, nor does it set any specific goals for transitioning individuals out of private ICFs in any given year. The program operates at the discretion of Health and in some years not a single individuals is transitioned into home and community-based services from private ICFs.
- 122. Over a 10 year time span, from 2006 to 2015, the State moved approximately 78 people from private ICFs to home and community-based services using the Transition program. This is nearly the same number of individuals the State moved in only 2 years during the inception of the portability program from 2000 to 2002. This disparity demonstrates that there are far more private ICF residents who want to leave their ICFs and live in a community-based settings than the State currently allows.

2. Utah's Transition Program for Individuals in Private ICFs

123. Individuals in private ICFs who wish to receive services in the community have little to no opportunities to transition to home and community-based waiver services.

- 124. The Transition program is the only mechanism Health provides to individuals who wish to move from private ICFs to home and community-based services. *See* Utah Admin. Code r. 414-510.
- 125. The Transition program has no dedicated funding, no waiting list, and does not assess an individual's desire or appropriateness for community placement. The program functions primarily as a lottery, selecting individuals using an arbitrary mechanism whereby individuals are chosen for community placement by sheer chance. State officials have likened to the program as akin to gambling in Las Vegas.
- 126. Under the Transition program Health alone decides on an annual basis if there are funds available to allocate slots to the program. Because there is no dedicated funding, the program operates entirely at the discretion of Health. The Division of Services for People with Disabilities has no opportunity for input despite their role in operating the Community Supports Waiver and making funding recommendations for the waiting list. *See* Utah Admin. Code r. 414-510-4.
- 127. Each year, assuming that Health has determined that there are funds available, Health then decides whether to invite eligible individuals to apply for Transition ("application years"), or to simply enroll all eligible individuals in the program that year ("enrollment years").
- 128. The discretionary decision to require applications or enroll all individuals into the Transition program each year rests exclusively with Health. This has created immense confusion for individuals living in private ICFs because the program can arbitrarily and fundamentally change from year to year without notice or explanation.
- 129. To be eligible for the Transition program an individual must be funded by Utah's State Medicaid Plan and have resided in a private ICF for 12 consecutive months as of July each

year. Therefore, an individual who moved into an ICF in August must reside in a private ICF for 23 months before they are eligible for the program.

- 130. Health does not require an individual to undergo any assessment for eligibility in the Transition program because the program assumes, and state officials have stated on multiple occasions, that all individuals currently residing in a private ICF can appropriately be served in a community-based setting. Accordingly, an individual who is qualified for the Transition program is also qualified to receive services through the Community Supports Waiver.
- 131. During application years, all eligible individuals must apply for the program anew, after receiving an explanatory letter and application that is distributed to individuals through the private ICF in which they reside.
- 132. This method of distribution relies heavily on private ICF staff to provide interested individuals with an application, answer questions about the program, and to support individuals interested in the program. As result an individual's knowledge and access to the Transition program is highly dependent on where they reside and whether staff at their private ICF make a good faith effort to provide full and accurate information about the Transition program.
- 133. On information and belief, there have been multiple occasions where a significant number of residents, and in some cases the entire population of a private ICF, have failed to receive the explanatory letter and Transition program application from Health. In other instances, private ICFs distribute applications only to those individuals whom staff subjectively considers to be appropriate for the program.

- 134. Some private ICF administrators have demonstrated that they hold views that are inconsistent with the purpose and intent of the ADA and *Olmstead*, views that undermine an individual's right to self-determination and other civil liberties.
- 135. For example, in October 2016, a private ICF owner that operates 4 private ICFs in Utah County with approximately 90 total residents sent a letter to family members of its residents concerning the Transition program. The letter actively discouraged family members from considering community placement through the Transition program and suggested that the program could result in residents being "forced to stop receiving services from [their ICF]."
- 136. The ICF letter further alleged that "advocacy groups in Utah have been trying to undermine parent's abilities to choose appropriate placements for their loved ones," and encouraged families to obtain guardianship rights so that they can prohibit advocacy groups (like the DLC) from speaking to individuals about the Transition program, and even offered to provide helpful resources if families "do not know where to start." The views expressed in this letter demonstrate why it is inappropriate to rely on facility staff to effectively disseminate and inform individuals about home and community-based services.
- 137. During an enrollment year, Health simply places all eligible individuals residing in a private ICF into the Transition program without requiring an application. All enrolled individuals are then sent an explanatory letter about the Transition program. This method of distribution also relies on private ICF administrators to provide individuals with the explanatory letter and answer questions about the program.
- 138. The Transition program materials prepared by Health are insufficient to provide private ICF residents with the information necessary for them to make an informed choice about

where they live. Those materials provide little, if any, helpful insight regarding home and community-based services and describe these services in very simple terms without appropriate context or clarification. Under previous iterations of the Transition program materials, some individuals in private ICFs did not complete a Transition application because they did not understand the program based on the language used in the letter.

- 139. Individuals who have submitted an application or been enrolled in the program are separated into two lists, a longevity list and a random list. On the longevity list individuals are ranked by their consecutive length-of-stay in a private ICF. On the random list, individuals are ranked based upon random selection. Individuals are then evenly selected first from the longevity list and then from the random list until the amount of funding available in a given year has been allocated.
- 140. Individuals who are selected are notified by letter, after which a staff member from Health will follow up with them by either a phone call or in-person visit. This process has proven ineffective for many individuals. Under the requirements of *Olmstead* and Title II, staff from Health should communicate the benefits of community living and should help an individual understand their options for support under the Community Supports Waiver during the visits. Yet, on at least two recent occasions there have been residents who received insufficient information to participate in the program and who were determined to have declined participation when in fact these individuals desperately wanted to live in a community-based setting..
- 141. Neither Health nor the State set measurable goals for the number of individuals to transition from a private ICF to a community setting each year. While Health staff claim that they move approximately 16 individuals each year, the actual number of those who transition varies

widely from 0 to 16 participants, which makes Health's reported numbers of individuals who transition unreliable and uncertain. Moreover, Health and the State have failed to dedicate any funding to the program regardless of the interest demonstrated by individuals living in private ICFs.

- 142. The Transition program also allows Health to reserve a number of slots each year for individuals who are involuntarily discharged from a private ICF and have no viable option for placement, thereby reducing the number of individuals who are able to transition because they are seeking community placement. This provides evidence that the Transition program is not a real deinstitutionalization mechanism and suggests further that the number of individuals purported by Health to be transitioned each year is unreliable.
- 143. Once the Transition program has ended each year there is no ongoing waiting list, or any effort to preserve information about the individuals who have expressed an interest in home and community-based services. As a result, individuals in private ICFs must therefore reapply each year the program is offered in order to be considered for placement.
- 144. In the 10 year time-span from 2006 to 2015, Health transitioned only 78 individuals from private ICFs to the Community Supports Waiver, at an average of 7.8 individuals per year or approximately 1.6% of private ICF residents annually. During this same time period, there were 4 years where the Transition program was not offered at all. This slow rate of transition fails to respond to the interest in community placement that many individuals in private ICFs have expressed over the years.
- 145. Health received approximately 70 applications in 2015 for the Transition program. In this single year, Health received as many applications expressing interest in community

placement as individuals Health has moved to the community through the Transition program in the previous 10 years. At Health's current rate of transitioning individuals in private ICFs to home and community-based services, it would take an additional 10 years to transition the 70 individuals who submitted applications in 2015.

- 146. By contrast, from 2002-2013 the Division of Services for People with Disabilities began serving 877 individuals from the Community Supports Waiver waiting list (approximately 3.5% per year). Individuals in private ICFs are transitioned onto the Community Supports Waiver at a rate that is half the rate of the waiver waiting list.
- 147. Further, Transition does not take into account the efforts an individual and their treatment team have made toward achieving community placement.
- 148. This stands in stark contrast to the Division of Services for People with Disabilities' administration of the Utah State Developmental Center, Utah's lone public ICF.
- 149. When an individual at the Utah State Developmental Center becomes ready for placement in the community, Developmental Center staff works with the Division of Services for People with Disabilities to invite community service providers to bid for the opportunity provide home and community-based services to the individual.
- 150. This bid process, like many others, is not available to any individual living in a private ICF. This is yet another example of how the State has segregated private ICF residents from the development disabilities service system and unlawfully limited their access to more integrated, community-based services

- 151. Apart from the Transition program, an individual residing in a private ICF who wishes to transition to the community may ask to be put on the waiting list for the Community Supports Waiver.
- 152. Individuals are taken off of the waiting list using a needs assessment tool in which individuals are ranked in order of most critical need. Because individuals in private ICFs are already receiving care, they are not considered to have a critical need and very unlikely receive a needs score high enough to qualify for waiver services. As one option for addressing this barrier, the State could choose to reserve a number of slots on the Community Supports Waiver waiting list, allowing individuals in private ICFs the opportunity to access home and community-based services in the same manner as other individuals with intellectual and/or developmental disabilities seeking services. However, the State has instead relegated this population to the Transition program, which, as constituted, violates Title II of the ADA and *Olmstead*.

C. <u>The State of Utah Fails to Demonstrate a Commitment to Deinstitutionalization for Individuals in Private ICFs</u>

- 153. The State's administration of the long-term care service system violates for individuals with intellectual and/or developmental disabilities Title II of the ADA and the United States Supreme Court decision in Olmstead, as well as Section 504 of the Rehabilitation Act.
- 154. Title II of the ADA requires the State to administer programs and services in the most integrated setting appropriate to the needs of qualified individuals with disabilities, which may require the State to make reasonable modifications to avoid discrimination on the basis of disability.
- 155. In *Olmstead*, the Supreme Court clarified that the reasonable modification standard could be met if a state were to demonstrate that it had a comprehensive, effectively working plan

for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated.

156. Unfortunately the State has not met this standard. The Transition program does not maintain a waiting list, seeks to keep private ICFs fully populated, and therefore does not constitute an effectively working plan that would serve as a defense to the allegations allege herein.

1. Utah's Service System Incentivizes Private ICFs to Maintain Full Capacity

- 157. In a 2015 report to the Utah State Legislature, the Division of Medicaid and Health Care Financing acknowledged that, in order to make a profit, private ICF providers must maintain a high bed occupancy rate. State officials have also publically acknowledged that at times the Transition program has been used to "ease pressure" on the private ICF system which is often at full capacity, rather than fulfill the State's Title II obligation of serving individuals in the most integrated setting.
- 158. As alleged, the State does not maintain a waiting list through the Transition program of individuals who wish to transition from private ICFs to the community, much less one that moves at a reasonable pace. Rather the Transition program is administered in such a way as to keep private ICFs fully populated.
- 159. Because a majority of individuals in private ICFs are Medicaid clients, the State of Utah is the largest payer of these services. Each private ICF is paid on a per diem reimbursement rate that is calculated by Utah Medicaid. As the agency responsible for overseeing the long-term care service system, the Division of Medicaid and Health Care has calculated a low daily rate that

does not correspond to an individual's service needs. As Health has acknowledged, this low rate requires private ICFs to maintain full capacity in order to sustain a viable operation.

- 160. Consequently, the State is unable to decrease the number of individuals residing in private ICFs without creating the risk that facilities will be unable to cover the cost of providing care. Health's administration of the long-term care service system thus actively discourages transitioning more than a minimal number of individuals in private ICFs to home and community-based services.
- 161. As a result, private ICFs have become permanent homes for a majority of individuals who want to, can, and should be better served in the community.

2. The State Does Not Have an Effectively Working Olmstead Plan

- 162. Because of the deficiencies alleged above, the State cannot properly construe its administration of the Transition program as an effectively working *Olmstead* plan or a defense to these allegations.
- 163. The State does not have a comprehensive, effectively working plan for moving individuals from private ICFs to less restrictive settings. In 2002 the State developed a document entitled "Plan for Comprehensive Services" that outlined certain goals intended to result in services for people with disabilities in the least restrictive setting. However, the last public update to this document was in 2003, and the last public mention of a State *Olmstead* plan was in 2007, which referred only to an *Olmstead* plan for the Community Supports Waiver waiting list and did not make reference to individuals in private ICFs.
- 164. The Transition program also fails to qualify as an effectively working plan as outlined by the Supreme Court in *Olmstead*. The Transition program lacks the essential

components of a plan including: measurable goals and time frames for moving individuals from private ICFs into home and community-based settings, dedicated funding, a waiting list of interested individuals, mechanisms for building capacity in the home and community-based service system, and effective planning among state agencies such as the Division of Services for People with Disabilities.

- 165. Additionally, the State has invested in the Transition program minimally at best. In fiscal year 2015 Health allocated only \$340,408 in general funds for the Transition program, compared to \$1,000,000 in one-time funding allocated by the Legislature as requested by the Division of Services for People with Disabilities to bring 176 individuals off of the waiver waiting list.
- 166. On information and belief Health fails to strategically plan with the Division of Services for People with Disabilities for the service needs of individuals living in private ICFs who wish to transition to a community-based setting through the Community Supports Waiver. This failure to work together further segregates individuals living in private ICFs from home and community-based services, because the Division operates the Community Supports Waiver. This waiver services approximately 5,000 individuals with intellectual and developmental disabilities. The Division has expertise assisting individuals to live in the community, yet Health has chosen to carve out the 600 individuals residing in private ICFs from the purview of the Division and prevented this population from meaningfully accessing the Community Supports Waiver waiting list.
- 167. The Transition program has not only failed to decrease the number of individuals residing in private ICFs but instead has been utilized as a mechanism, through Health's

administration of the program, to ensure private ICFs maintain full capacity, without regard to the needs or desires of individual ICF residents.

- 168. The State has made efforts to fund individuals on the Community Supports Waiver waiting list, however, these investments are not for the individuals residing in private ICFs and have not assisted members of the Plaintiff Class to move to a less restrictive setting. To the contrary the State's administration of the service system has excluded members of the Plaintiff Class from accessing the waiting list, and prevented individuals from transitioning on to the waiver solely through the Transition Program.
- 169. Moreover, individuals in private ICFs are essentially divorced from entering the community through Community Supports Waiver waiting list. Many individuals in private ICFs are unaware of the waiting list and those who are on the waiver waiting list are unlikely to be assessed with a needs score high enough to merit placement on the waiver. Therefore, the only mechanism available to individuals in private ICFs is the Transition program.

3. The State's Recent Efforts to Improve the Transition Program Fail to Address the Problem

- 170. In June of 2017, Utah Medicaid convened a group of stakeholders to discuss how the Transition program could be improved. Staff from Utah Medicaid and the Division of Services for People with Disabilities were in attendance, as well as disability advocates and private ICF staff.
- 171. During the meetings Utah Medicaid announced they would use the enrollment selection process for the Transition program in the fiscal year 2018. Under the enrollment process, all eligible individuals residing in private ICFs are ranked on the longevity and random lists. Individuals are then selected until all available funding has been allocated. Utah Medicaid also

announced that it would visit every private ICF in the State to give a presentation on the Transition program.

- 172. Utah Medicaid also proposed, but has not adopted, a scoring mechanism for the Transition program that would replace the longevity list but would keep the random list intact. Under the proposed scoring, an individual would receive a higher score the longer they have lived in a private ICF. Utah Medicaid also proposed to award a higher score for each consecutive year an individual has applied for the Transition program, despite concerns from stakeholders that individuals do not submit consecutive applications because individuals are discouraged after multiple unsuccessful attempts to secure a spot on the Community Supports waiver through the Transition program.
- 173. These recent efforts by Utah Medicaid are not sufficient to remedy the discriminatory segregation experienced by members of the Plaintiff Class.
- 174. As alleged above, the Transition program does not comply with the requirements of Title II and *Olmstead*, and merely expanding the Transition program to include all eligible individuals-a process that is already currently available, does not remedy these ongoing violations.
- 175. Similarly, providing a single, group presentation on the Transition program is an inadequate substitute for the one-on-one in-reach efforts that are the most effective way to inform individuals about home and community-based services. Moreover, the minimal efforts that were made to notify individuals about the Transition program presentations were flawed, and in at least one instance, individuals and families received a notification letter announcing the presentation the day after Utah Medicaid had given its presentation.

- 176. Furthermore, the State has not addressed the complete absence of measurable goals and dedicated funding for the Transition program throughout the stakeholder process.
- 177. During the stakeholder meetings, hallmarks of *Olmstead* planning were absent or rejected, such as conducting evaluations of a resident's appropriateness for community placement, dedicated or increased funding, or increasing the number of individuals who are transitioned to community placement each year.
- 178. Ultimately, the meetings made only slight improvements to a program that is inherently non-compliant with the requirements of Title II and *Olmstead* and did not address the key components of an effectively working *Olmstead* plan.
- 179. Members of the Plaintiff Class are capable of living in the community and do not oppose community placement. Many of the individuals to whom the State currently provides home and community-based long-term care services have physical conditions and functional capacities that are the same as, or are similar to, the class members currently living in nursing facilities. In State documents, officials acknowledge the individuals served by private ICFs are not significantly different from those served in other systems serving people with disabilities.
- 180. Providing the Individual Plaintiffs and the members of the Plaintiff Class with access to the integrated residential services required to remedy their unnecessary institutionalization would not fundamentally alter the State's service system for people with intellectual and/or developmental disabilities. State officials have acknowledged on numerous occasions the benefits of community living and that home and community-based services are more cost effective than institutional care. The Division of Services for People with Disabilities stated in its fiscal year 2016 annual report with regard to the implementation of federal regulations

impacting home and community-based settings that: "We are committed to adjusting our policies to ensure people receiving our services are fully integrated within the community they reside and not systematically limited in their ability to live self-determined lives." This statement demonstrates the State is capable of making reasonable modifications to serve people in the most integrated setting possible.

- 181. State officials have acknowledged they can appropriately serve anyone residing in a private ICF in a home and community-based setting and that these services are generally less expensive. In a 2012 Social Services Appropriations Committee hearing, the former director of the Department of Human Services stated that "the department has instituted Community Supports Waivers which are much less expensive services, allowing individuals to function, rather than being housed." The Community Supports Waiver already provides the appropriate supports to serve individuals living in private ICFs, and the State needs to provide members of the Plaintiff Class with meaningful access to these services in a manner that complies with the Title II of the ADA and *Olmstead*.
- 182. On December 19, 2016, counsel for Named Plaintiffs sent a letter to the State detailing violations of Plaintiff's rights under Title II of the ADA and the Supreme Court's ruling in *Olmstead*. The letter outlines the State's policies and practices that violate the integration mandate of Title II of the ADA.
- 183. Plaintiffs' counsel has met with the Governor Herbert's designees, and designees from Health and Human Services on several occasions over the past year, in an effort to address the concerns raised in the December letter.

184. At this time, the parties have been unable to make significant progress towards a resolution of the violations identified in the December letter, and it has become necessary to proceed with this lawsuit.

VII. CAUSES OF ACTION

CLAIM ONE

(Violation of Title II of the Americans with Disabilities Act)

- 185. The allegations of Paragraphs 1 through 184 of this Complaint are hereby re-alleged and incorporated by reference.
- 186. Each Named Plaintiff and class member is an "individual with a disability" within the meaning of the ADA in that they have disabilities that substantially limit one or more major life activities, such as self-care, learning, working, and brain function. 42 U.S.C. §§12102(1)(A), 12102(2).
- 187. Each Named Plaintiff and class member is a "[q]ualified individual with a disability" within the meaning of the ADA, 42 U.S.C. § 12131(2), because he or she is qualified to participate in Defendants' more integrated, community-based programs and services.
- 188. Defendants Joseph Miner, Ann Williamson, Nathan Checketts, and Angella Pinna ("Officer Defendants"), acting in their official capacities, are public entities covered by Title II of the ADA. Therefore, the ADA prohibits the Officer Defendants from discriminating against individuals with disabilities in its programs and services. *See* 42 U.S.C. §§ 12131 and 12132.
- 189. Under ADA Title II implementing regulations, "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

190. The unnecessary institutionalization of the Named Plaintiffs and class members by the Officer Defendants is a violation of Title II of the ADA and its implementing regulations because the Officer Defendants have failed to remedy their segregation in private ICFs by providing access to home and community-based services.

191. Further, regulations provide:

A public entity may not, directly or through contractual or other arrangements, utilize criteria or methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; [or] (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities.

28 C.F.R. § 35.130(b)(3)(i)-(ii).

- 192. Officer Defendants have administered their programs in a way that caused the Named Plaintiffs and class members to be unnecessarily institutionalized in private ICFs in order to receive long-term care services, rather than providing them with appropriate services and supports to live in the community, in violation of Title II of the ADA.
- 193. In so administering, Officer Defendants have caused the unnecessary segregation of the Named Plaintiffs and the members of the Plaintiff class.
- 194. In so administering, Officer Defendants have failed to operate their service system in such a way as to make services available in the most integrated setting appropriate to the needs of the Named Plaintiffs and the members of the Plaintiff class.
- 195. In so administering, Officer Defendants have caused Named Plaintiffs and the members of the Plaintiff Class to be treated on grounds not equal to those of their peers in the community.

- 196. Such administration has the effect of defeating or substantially impairing the objectives of the service system with respect to Named Plaintiffs and the members of the Plaintiff class.
- 197. Providing access to integrated residential service to the Named Plaintiffs and class members would not fundamentally alter the Officer Defendants' service system for people with intellectual and/or developmental disabilities.
- 198. Defendants lack a comprehensive and effectively working plan designed to provide the level of home and community-based services necessary to remedy class members' segregation.
 - 199. The Officer Defendants' actions violate Title II of the ADA.

CLAIM TWO

(Violation of Section 504 of the Rehabilitation Act)

- 200. Paragraphs 1 through 199 are incorporated by reference.
- 201. Under Section 504 of the Rehabilitation Act, "No otherwise qualified individual with a disability ... shall, solely by reason of her or his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 29 U.S.C. §794(a).
- 202. Defendants administer the programs in question with Medicaid, a federally funded program, and, thus, receive federal financial assistance within the meaning of Section 504.
- 203. Each Named Plaintiff and class member is an "individual with a disability" within the meaning of Section 504 because they have disabilities that substantially limit one of more major life activities, such as self-care and social interaction.

- 204. Each Named Plaintiff and class member is a "qualified person with disabilities" within the meaning of Section 504 because he or she is qualified to participate in Defendants' more integrated, community-based programs and services.
- 205. Section 504 implementing regulations require a public entity administer its services, programs, and activities in "the most integrated setting appropriate" to the needs of qualified individuals with disabilities. 28 C.F.R. § 41.51(d).
- 206. The unnecessary institutionalization of the Named Plaintiffs and class members by Defendants is a violation of the Rehabilitation Act and its implementing regulations because Defendants have failed to remedy their segregation in private ICFs by providing access to home and community-based services.
- 207. Section 504 regulations further prohibit recipients of federal financial assistance from:

[U]tiliz[ing] criteria or methods of administration ... (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, [or] (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program with respect to handicapped persons.

45 C.F.R. §84.4(b)(4)(i)-(ii); 28 C.F.R. §41.51(b)(3)(i)-(ii).

208. Defendants have administered their programs in a way that caused the Named Plaintiffs and class members to be unnecessarily institutionalized in private ICFs in order to receive long-term care services, rather than providing them with appropriate services and supports to live in the community, in direct violation of the Rehabilitation Act.

- 209. Through the administration of their programs, Defendants have caused the segregation of the Named Plaintiffs and the members of the Plaintiff class from the rest of the community.
- 210. Through the administration of their programs, Defendants have failed to operate their service systems in such a way as to make services available in the most integrated setting appropriate to the needs of the Named Plaintiffs and the members of the Plaintiff class.
- 211. Through the administration of their programs, Defendants have caused Named Plaintiffs and the members of the Plaintiff Class to be treated on grounds not equal to those of their peers in the community.
- 212. Such administration has the effect of defeating or substantially impairing the objectives of the service programs with respect to Named Plaintiffs and the members of the Plaintiff class.
- 213. Providing access to integrated residential service to the Named Plaintiffs and class members would not fundamentally alter Defendants' service system for people with intellectual and/or developmental disabilities.
- 214. Defendants lack a comprehensive and effectively working plan designed to provide the level of home and community-based services necessary to remedy class members' segregation.
 - 215. Defendants' actions violate Section 504 of the Rehabilitation Act.

VIII. PRAYER FOR RELIEF

WHEREFORE, Named Plaintiffs and class members (together, "Plaintiffs") respectfully request that the Court:

A. Certify this action as a class action pursuant to Fed. R. Civ. P. 23(b)(2);

- B. Issue a declaratory judgment that the Defendants' failure to provide Plaintiffs with long-term care services in the most integrated setting appropriate to their needs violates Title II of the Americans with Disabilities Act;
- C. Issue a declaratory judgment that Defendants' failure to provide Plaintiffs with long-term care services in the most integrated setting appropriate to their needs violates Section 504 of the Rehabilitation Act;
- D. Enter a permanent injunction requiring Defendants to promptly take the following necessary steps to serve the Plaintiffs in the most integrated settings appropriate to their needs:
 - i. Develop and implement a working plan for identifying and transitioning individuals with intellectual or developmental disabilities from private ICFs into home and community-based services, including by providing appropriate information and supports and conducting appropriate assessments of all residents to determine individual preferences.
 - ii. Evaluate, improve, and expand the services that support individuals with intellectual or developmental disabilities so that individuals who reside in private ICFs and are not opposed to leaving may live in integrated, community-based settings.
 - iii. Reduce the State's reliance on segregated, institutional care in private ICFs for individuals with intellectual or developmental disabilities in Utah.
- E. Award the Named Plaintiffs and class members their reasonable attorneys' fees and costs pursuant to 42 U.S.C. § 12205, 29 U.S.C. § 794a, and any other applicable provision of prevailing law; and

F. Grant any other relief which is necessary and appropriate to protect the federal rights of the Named Plaintiffs and the class members they represent.

DATED this 12th day of January, 2018.

/s/ Juliette P. White

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Attorneys for Plaintiff and Proposed Class Members

CERTIFICATE OF SERVICE

I hereby certify that on the 12th day of January 2018, I caused to be electronically filed the foregoing with the Court by CM/ECF and the Court will send electronic notification to all counsel.

/s/ Juliette P. White