Giving a Voice to Families and Guardians:

A Survey of Families and Guardians of Individuals with Intellectual and Developmental Disabilities in Various Residential Settings

VOR

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This survey sought to capture the viewpoints of family members of individuals who reside in ICF settings, a group under-represented in surveys, and to compare their responses with the responses of family members of individuals residing in Non-ICF settings (home and community-based settings), to the degree possible.

The Executive Summary and Detailed Results are available here (LINK TO BE ADDED)

The following are the answers provided to this question:

> "***What would you like our government to know about the current move to de-institutionalize ICF residents in favor of small community-based facilities*?"**

Names of individuals, states and providers have been blocked out.

ICF Survey Responses begin at page 4.

NON-ICF Survey Responses

1. Please provide "treatment", not just custodial care...even for older DD kids

2. De-institutionalization has a far broader meaning to these advocates than just closing ICF's. They also want to close group homes and all other congregate programs including work and day programs. They do not seek out opinions different from their own and are dismissive of family members and family organizations trying to preserve a full range of options. They also rely heavily on government funding, an inherently unfair and ultimately harmful use of taxpayers' money.

3. These people are individuals and need to be offered the choices that best meet their needs whatever that choice may be.

4. I'm against it.

5. "I pray that he will always be in the ICF because he could not function in a community setting as he requires assistance with all personal hygiene, dressing and all daily activities, even eating.

6. He along with millions of others just could not survive outside"

7. While I understand that small group homes are not for every client, my son has benefitted greatly from being in a small group setting, as opposed to the state developmental centers and large group home he has resided in. He has been in two state developmental centers and one large group home where he experienced theft, fraud, abuse and neglect. He has received much more individualized care in the small group homes, and enjoys the many advantages and home-like setting they offer, as well as the regular medical care he receives. My son has many medical and behavioral problems, which [REDACTED] has dealt with exceptionally well. I hope my son can stay there as long as he lives.

8. I believe the home receives over $20,000 monthly for his care, because he needs 2 or 3 people to restrain him when he becomes violent. Unfortunately, they have no training in this area, as was the situation at [REDACTED] State Hospital. Nothing could have been worse for him then being forced out to live in a community home, which was shut down when client died. He was then placed in the home-- [REDACTED] in [REDACTED]. Because of his violence, I don't have any choice, especially now with all the unfair cutbacks. Maybe the situation would be different if some of the Congressional leaders had a child or other close family member in these inadequate group homes. All I can do is pray and be thankful for all your organization does. It is a sin for the government to shut down facilities which have trained, educated personnel, and adequate facilities for the care and safety of our loved ones.

9. Small community settings use medication for behavior control much more than SODCs.

10. To deinstitutionalize means failure. The need for specialized caregivers would be far greater than they are now and I feel the cost would be prohibitive, especially since the salary to private providers is lacking and you start to go to the bottom of the barrel in who you hire and the responsibility and liability that goes along with this hiring.

11. I'm not sure that there should be an overall de-institutionalization. Some clients need an ICF.

12. It is not for everyone, especially those at end of life. Group homes are appropriate only for high functioning, not profoundly or those needing total care with complex medical issues. Would you put 4 alzheimer or memory care seniors in a group home of 4-8 with one aide, who also may have seizures---totally unrealistic. Support families who are willing to care for their loved ones at home---that is the best care if they are able

13. Unfair and illegal if it's forced. My sister is not capable of being mainstreamed. Her condition is so extreme - shocking, in fact - that any setting that she is placed in will have to be RESTRICTIVE - regardless of where the setting is. That is the hand that she has been dealt.

14. "This is blatant disrespect for family guardian choice.

15. The government's biases are no less than a declaration of war against vulnerable people."

16. "One size does not fit all

17. What happen to the rights of people to live where the what to?"

18. One "size" does not fit all. Not everyone functions at a high enough level that they can become part of the "community" and become a "productive" citizen.

19. In [redacted] the training centers provide safe and secure environment that a group home cannot

20. yes... it is up to the families to decide. For some residents of ICF , it is too stressful for them to leave all they know. No one has the right to take them from their home and the people who have loved and nurtured them throughout their lives!!!

21. Background checks are only if convicted. A person can go facility to facility & since the courts will not use testimony of a retarded person they are never convicted whether is sexual abuse, physical abuse or verbal

22. Before releasing individuals to the community make SURE there is an appropriate facility in place and then make SURE inspections and care are done properly in order to meet every human beings need for cleanliness, nutrition, friendship, recreation and dignity

23. Institutionalization is not a sterile cold unfeeling choice for families whose loved ones live with multiple or profound disabilities. My sister lived at her facility for 37 yrs-she was taught to feed herself and walk, things that we, her family, would have never dreamed were possible. She had easy access to doctors and therapists and she lived with her peers. She has lost the ability to walk and feed herself after 2 yrs in the apartment. People with disabilities deserve better-shame on our government

24. we are in a state facility in LA. Specialized people always working with clients. Always attentive to medical needs and what were better, educational ideas for client, my daughter. Very clean considered intellectual status of my daughter needs. Protected-nurses on staff, social workers, therapists are all attached to the individual

25. I don’t want my son in a group home. I have visited one and they had a small jar of milk of 8 people and one bowl of food on the table for all the residents and they didn’t have enough beds for all of them to sleep in and I asked where is your medicine kept is it locked up and they said yes, but it wasn't. I have been in stores with then and they made some of the clients take care of other that couldn't shop and wasn't concerned about the ones that went outside the store

26. He hasn't been there long enough but he is adjusting fine

27. we have 2 disabled children-our daughter lives in a group home, it’s a constant battle to see her care done well, from a low fat, low salt, low calorie diet to her daily activities in the home to dressing her properly and interaction with the staff. We also have a son who has been in an ICD since her was 6, his care is top quality, we are against placing him in a group home

28. My child likes his group home. He enjoys going to accent, fair, church, circus, movies and special olympics

29. My son was in the community until he was 11 years old. He couldn't cope and neither could I. He is happy where he is

ICF Survey Responses

1. He would not have the on-site adequate care he needs.

2. ICF's offer residents with myriad different mental and physical disabilities more opportunities for medical, occupational, physical, nutritional educational, and social care than a community-facility ever could. Doctors and nurses are there 24 hours a day for any medical need, no matter how big or small. Other specialists are there every day to ensure each resident’ individual needs are met daily. In a smaller community based setting it would be impossible to provide such personalized, round the clock care.

3. Community-based facilities are not the best living situation for everyone needing full time care services. Institutions provide excellent care and economy of scale. Institutions provide the opportunity for nurses, doctors, speech therapists, occupational therapists, physical therapists, nutritionists, etc, to be on site every day to meet residents needs at all times. Anytime a situation arises these people are right on site - and able to serve many people all in one place. This also allows for these employees to get to know these residents' very well and understand their individual needs.

4. One size does not fit all.

5. Parents and Gardenias should have a choice to where they want to put their disabled child, not all disabled people fit in a small community based facility and not all disabled fit into ICF places.

6. 4 of our adopted sons and daughters have developmental disabilities: 3 do fine living in their apartments with support services as needed and that is their choice and right for them; our autistic son needs highly trained staff with low turnover, careful medical care and immediate availability of medical care, professional attention to his dietary needs by a dietitian and the staff, a coordinated program to deal with his behavioral needs, and a trained person plus a driver 3 days a week to take him to dialysis and to sit with him every minute of dialysis. No

small community-based facility can meet his needs, and failure to meet them would not only make him miserable, it would be deadly.

7. If ██████ Center is closed, my brother will have to be placed in another institution or a nursing home. His health is very fragile, he is susceptible to pneumonia, and I would fear for his life in a private home.

8. The level of services and support offered to "group home" and CILA residents do not come close to those provided in an institution such as ██████ Center. Many individuals require those services, others do not. Some people have severe behavior disorders and may pose a threat to themselves and others. It takes trained staff to handle those individuals.

9. My family is very grateful for the services provided to my twin brothers born prematurely in 1960. One of the twins has passed away but one remains. He gets excellent care. At the time when they were at home they were so challenging that my loving parents could no longer care for them. Most people do not understand what it is like to try to care for such needy individuals even when you love them. There is a great need to keep both small community settings AND places like Woodward with the experts and services to care for our most difficult individuals with services needed right on campus. MY brother finds comfort in this setting and gets the care he needs for significant health and behavioral needs. The staff are excellent, caring and knowledgeable. Last week while I was visiting my brother had a seizure and code blue. The staff acted quickly and within minutes he had nurses and a Doctor at his side. These people know him and his needs. They knew immediately what to do for his specific needs. I'm so thankful for the care they give my brother. Thanks.

10. My daughter has been in ██████ center 41 yrs. with the best of care and .is so severely mentally and physically disabled if she would be put in a CILA home she would not last 6 mos. ██████ has on grounds medical staff that is able to attend to her in a min. notice. The state ████ is trying to close this facility and it is badly needed.

11. Many intellectually disabled people need the services provided by our state operated developmental center. My brother is 61 yrs old and operates on a 3 yr old level and does not speak. He is best served in the state operated facility in which he currently resides.

12. My brother is currently receiving the high quality specialized care that allows him to live a happy and comfortable life. Because of his disabilities he would not be able to interact with the community any more in a group home than in his current home in a state center. A move would mean that he would lose the caregivers and friends that he has known for the past 50 years and be thrust into an environment populated by strangers. He is currently 67 years old with medical problems from head to toe. He would lose the on-site medical care that has kept him living for the past 50 years. In short, he would lose what he needs and desires and gain nothing in return.

13. Very few residents would receive quality care in community facilities.

14. IT MAKES NO SENSE GOV. NEEDS TO DO MORE RESEARCH IN THE RIGHT PLACES

15. Moving residents into small community based facilities is not a one size fits all solution. My individual would not be provided the services that he needs in such a setting and would be in danger.

16. When ████ Center was closed, ██████████, We checked 6 small community-based facilities. None could provide the health care she required to live.

17. dont move them

18. This arrangement is not for everyone. You will need to provide a backup system for emergency/crisis management. You can find this arrangement in most ICF/MR Settings.

19. YES

20. SUPREME COURT OLMSTEAD DECISION, ADA, & MORE SUPPORT GUARDIANS' CHOICE! STOP DOJ & ANY OTHERS WHO ARE FORCING CLOSURES OF ICFs!

21. We need our resident facilities. Group homes cannot give the care for my son and so many others that facilities can give. Poor staff, no medical facility willing to see these individuals and if they did, they do not know how to handle them.

22. We were always pleased with ████'s ICF placement. He was moved to a nursing facility and we were very unhappy with his care. We requested that be returned to ██ where we knew he would get the kind of care we wanted for him. And, he did.

23. One program does not fit all. Rural communities do not have medical familiar with the severely handicapped.

24. One size does not fit all. Some individuals will always the care provided at the ICF. If we consider the term of "least restrictive environment", an ICF may provide this over a community based model.

25. I would like them to know that an ICF is the best choice for some disabled people. We need more choices for our most needy people---not less.

26. Don't close facilities until alternative placements have been in place and are known to be working and until a sufficient number of physicians and dentists are willing and available to serve this population.

27. Severely incapacitated individuals' lives will be endangered if they are shoved out the door to community settings where there is a limited framework to support then safely.

28. Does not sound cost effective for profoundly disabled.

29. Until the federal government has walked in my shoes, they need to stay out of my business.

30. Smaller institutions aren't able to provide the services we get on campus

31. The policy of de-institutionalization of ICF residents is being forced upon families despite their objections. Families and other guardians are being ignored. Residents are being put in harm's way because of inadequate services in the community to serve residents now living in ICFs, who have the highest degree of disabilities. ICF care is comprehensive, consistent, cost-effective, successful, stable and sustainable.

32. Please consider talking to the parents and families of these residents. Change is very hard for these patients. We as family would only do what is best. Please don't mandate change

33. That our loved ones families should have a voice on where our loved ones would like to live. These individuals are most disabled mentally and physically. They deserve to reside in a developmental center where there medical and social needs will be met and no dictated by government officials who do not understand their level of disability and are only concerned about saving the State money which is not even the case. Our most vulnerable deserve better. We as their guardians know what is best for our loved ones. If they were not getting the proper care from the developmental center, they certainly would not reside there. Just like any parent knows what is best for their child. I wish we would be regarded with the same level of respect for our loved ones.

34. It would be a dis-service to our loved ones to plan to close an ICF-Developmental Center. Our loved ones with severe and profound disabilities are well served both medically, socially and emotionally in our Developmental Centers and the sensitive kind of care cannot be replicated in a community setting with lack of a sufficient and qualified persons serving in direct care and also the lack of the federally mandated active treatment plans which are practiced at our ICF/Developmental Centers. Our loved ones have access to the community inside and outside the ICF-developmental center via family, friends, businesses, volunteers who continually visit and support our loved ones in the ICF/developmental center, plus the quality of on-site medical care is outstanding and consistent. Please save our ICF/Developmental Centers!!!

35. Her life is not limited by where she lives, but by her level of development. Most residents of ICFs at present are in this situation.

36. They are wonderful. They are safe havens. Our brother was in 4 community settings and they didn't work. The govt figures are flawed and dishonest.

37. We need all levels of care and all types of homes for individuals to be served well and live good lives. Small community based homes should only be one choice of several available to a person. People with intellectual disabilities need the same range of choices as a senior citizen contemplating where they will live.

38. I do not believe it is for all residents to be in a small group home. There are those who cannot be comfortable or safe in that environment.

39. Prefer RHC (Institutional) care as it offers the most protection and services.

40. It is a denial of justice.

41. They do not have the same level of care and availability of medical treatment for the severely retarded.

42. That all individuals do not fit into community living and need the care they are receiving 24\7

43. ICF facilities are an absolutely necessary part of the spectrum of services needed to meet the needs of all members of the IDD population - ICF addresses needs of the most vulnerable people with IDD.

44. be sure that a community based facility can provide all the same level of care as the ICF for each individuals needs

45. My sister has been in a community residence program and she was not only extremely unhappy, but she developed significant behavior problems. One time, they even thought she had run away in the middle of the night and had numerous law enforcement agencies as well as individuals searching for her for hours. She most definitely cannot function properly in this kind of setting. She needs more direct care. My family and I are totally opposed to a community residential setting for our sister.

46. My sister would not have the quality of life that she does now. She would NOT be able to live in a small community based facility. She does not function at a level that would ensure her health and safety outside her present community setting.

47. Very important to keep ICF for our daughter, she functions well in the setting she is in. For severely handicapped, ICF is by far the optimum choice.

48. This would be a potentially lethal mistake. The risk of damage: medical, emotional, behavioral is quite high.

49. I think the Fed. Government needs to know that choice is very important and the ICF/IID is a preferred choice for many. They have no business closing centers without our consent.

50. ICFs are a part of the community. ICFs provide a needed service for this fragile population.

51. Icf facilities sometimes DO provide the best least restrictive environment for many disabled individuals who are unable to do things for themselves and who require 24 hour care and specialized medical attention. The icf facility provides the special care , while at the same time they are able to provide activities on campus and provide transportation and appropriate activities off campus. These special citizens would NOT be given the same quality care or opportunities in a small setting away from a mainstream of experience and service availability.

52. We MUST have a continuum of residential services - of which ICF's are an integral part!

53. "Re: #25: My answer presumes my sister's community to be her RHC-Nursing Facility. I don't have any recent-enough broader community photos of her

54. #27: What we continue to need is a seamless continuum of residential choices that includes larger facilities that provide centralized, on campus services for those whose capacities and needs differ from those who can benefit from community-at-large inclusion. Olmstead supports the choice of institutions under circumstances in which the person's independence is better supported in an institution. This is the case for a great many individuals with i/dd who have particularly low functional abilities and/or high acuity needs. In the case of my sister, whose personality is highly social, she thrives on the interaction of the many people who surround her on a daily basis during the course of her therapies, supported workshop and recreation as well as at home. (All of this is affordable only because of the economy-of-scale of sharing resources.) When separated from her housemates, it is plain that she misses them. When she comes home from an outing, even though she enjoyed it, her pleasure at being home in her congregate care environment is palpable. Because of centralized services + well-supervised, well-trained, low-turn-over, caring staff, her life is rich with experiences that are geared to her level of development. She is happy. I would like the government to reject all one-size-fits-all notions that assume everyone with i/dd should be housed in the community-at-large. Our society does not condemn universities for providing centralized services, nor do we insist all students live off campus. We don't prohibit seniors from living in congregate facilities with varying degrees of centralized services. We don't insist that all students be in classrooms of only 2 or 3 students. We utilize hospitals that centralize services, recognizing that there is efficiency and economic

value in such sharing of resources. To deprive people with i/dd of the choice to live in congregate care adds up to ideological discrimination against them. To devote all or even the preponderance of public money to off-campus residential choices for people with i/dd is also discriminatory, especially when pressure is brought to deprive people of making such choices in the first place."

55. It would be disastrous in the case of my sister, and others I know. She's happy, healthy, productive AND protected on campus.

56. Individual Choice and the continuum of care are important in the RHC's. It seems to empower the RHC client. They love to feel the control they have.

57. community services does not have the resources that my daughter needs in the community

58. it doesn't work for all individuals - choice should be available

59. Dual diagnosis individuals are not safe outside of the state ICF. It would take more space than allowed here for me to fully explain but in past time when he was in community homes it was a disaster

60. One size does not fit all. Small community-based settings are probably the best solution for clients with only mild developmental disability. Multiple problems involving physical and mental illnesses as well as profound developmental disability require specialized care services.

61. Most residents have spent the majority of their life receiving services at their current location. Change is difficult for all people but extremely difficult for dev. disabled individuals.

62. Older residents with medical and mental issues may be better served in a facility with the 24-hour supervision of medical personnel that they know and trust.

63. Gov't must realize that community placement is not cost effective when compared to the VA training centers. It has been shown that financial cost studies secured by ARC and others and accepted by Gov't are skewed. Nor is community placement a safer or more nonrestrictive environment. ████ is the most safe and nonrestrictive place to live for my son (I/DD), and many others in his category, where residents receive outstanding medical care and observation. If residents or their authorized representatives desire a resident's placement into the community, they may voluntarily do so at any time or to any selected place. It's time to appropriately downsize some ICFs, etc, which is actually being partially accomplished with many residents voluntarily leaving for a community placement. My son and many other residents are not candidates for community placement. Downsizing is a strong option and may also be applicable to ICFs nationally.

64. Most communities do not have anywhere near enough community-based facilities that are anywhere capable enough to accommodate him.

65. De-instituationalize can harm patients.

66. Community based facilities cannot meet the many needs of the severely intellectually disabled and medically fragile individuals currently being service in developmental center. Group home are not adequately staffed with qualified workers and receive limited oversight. ICF/MR facilities follow strict standards of care and receive regular oversight. Forcing these medically and behaviorally fragile individuals into community based living with 2-4 bedrooms put them at risk for abuse and neglect. It also results in fewer services which is a violation of their federal rights.

67. Yes, to know how it is against the wishes and well-being of these disabled people.

68. This is a gross error that favors inappropriate care; incompetence and poor oversight. Governmental decision makers need to know that this family's personal experience found a lack of adequate medical care; a lack of adequate supervision; little, if any, agency or governmental oversight in three different, small community-based settings. After exhaustive years of trying small community options, our son's hospitalization finally brought us to his current ICF Care Facility in ███████. Our son, now 45, is thriving, productive and living a fulfilling life. The staff is remarkable, well trained and on top of the day to day challenges presented by autistic adult males. The worst part? The staff is poorly paid for the exhausting work and compassion they provide each resident."

69. A small percentage of persons with developmental disabilities need services designed especially for them: language help, many have little or no speech. Help bathing, toileting, special diets, medical supervision, dental services and more. ICF residents require constant supervision, close care, special diets, and more. They have no sense of ordinary hazards, traffic, use of money, They need constant supervision by familiar staff. They may need specially prepared food. Help in communicating, many have no speech, or little speech, no sense of the use of money. Many need help with toileting and personal care. Stable staff is most helpful, desired and more likely to be found in an ICF.

70. Currently, the individual is overlooked for a broader attempt to have everyone live in the community. Yet nothing is said about the probability of overwhelming the community supports & services with an influx of high needs individuals.

71. These most severely disabled residents of state run ICFs would lose the onsite health care, 24 hour nursing, active treatment, dental care, on site workshop, experienced long term direct care workers and a safe environment if they were moved to small community-based facilities. One size does not fit all!"

72. Small community-based facilities are OK for some but not for everyone. You cannot force people to fit a mold just because it suits your purpose.

73. It is very ill-advised. There are very different needs that require different residential solutions.

74. The current community supports are not yet strong enough to handle our most fragile IID. Most of the community medical/dental/vocational agencies are not cognizant of how to deal with this type of IIDs. The entire outside community would need to be trained in dealing with IIDs. This would be an impossible feat - to train every doctor, nurse, dentist, medical technician, employer, etc. It is much better to have a small handful trained to care for our loved ones that can provide stability and consistency in the lives of our most vulnerable.

75. One size does not fit all. The specialized care some individuals require cannot be met in community-based facilities. Their needs are too great.

76. Government shows unwillingness to admit failure of this policy in many instances.

77. ICF offers by definition more specialized and coordinated supports and services than waiver programs. Not all community based areas can provide full level of services. Our adult child was in waiver services and because of inadequacies led to crisis situation that was unresolvable until placed in state ICF.

78. The adverse and unintended consequences of deinstitutionalization are grave, and they are already happening in states that do not provide comparable community services, supports, and accountability. The community must be fully prepared to receive those with severe and demanding behavioral and medical needs prior to forcing closures of high quality institutions. This will not be achieved quickly or cheaply, and if done properly will result in no financial savings -- in fact, offering the same level of necessary services will require the same level of expenditures, and those in need of daily medical attention will cost more in community settings. Ideologies should never determine medical decisions, and families are the only people with pure motives regarding placement decisions. States should offer every care option and setting for this diversely impaired population, and supply each option without prejudice or bias.

79. The government must learn the value and necessity of ICF's and began supporting their existence. They should stop with their de-institutionalize programs.

80. The community does not always provide the supports some of our disabled folks need and is not always a welcoming place. for some, the least restrictive environment is a structured setting. If the disabled are to have the same or similar opportunities as the rest of the population, those opportunities must include choice and a range of good options.

81. I am NOT in favor!

82. Small community-based facilities will compromise the quality of life for residents. Direct care staffing will experience greater turnover, less training, less experience, less commitment to the job leading to less than adequate care for residents. Fewer staff to draw from will negatively impact the provider's ability to cover unplanned absences leading to periods of inadequate staffing and much lower levels of care.

83. One size does not fit all. There is a need for ICF-DD/ID facilities as well as community based programs. Families/guardians know better where their loved ones needs are met. Forcing the profoundly disabled into community programs puts them at risk for care of lesser quality as well as putting a strain on the community programs.

84. "It is a bad idea promoted by people who either do not understand the DD population or expect to make a profit form deinstitutionalization. Comparable levels of care in the community are prohibitive and they know it.

85. There should be choices available for all. My sister thrives in her setting. No one has the right to take that away from her. Our constitution gives us this liberty-just because my sister cannot speak for herself does not mean others can take her from her home because of what THEY believe.

86. Small community-based facilities are not appropriate for the severely disabled (like our daughter). She would be isolated. Would the neighbors invite her for coffee, or dinner? I seriously doubt it! With a small number of staff, there would be more chance of abuse. We are happy and our daughter is happy with her current placement!

87. Some individuals simply cannot function in such an environment without constant supervision by professional staff. In a community based setting, they could well be a danger to themselves and to others simply because they lack the developmental/intellectual/social ability to function within in such a facility, which would also require an ability to integrate into the surrounding community.

88. We are quite happy with the care my brother receives at Polk center. He is deaf, cannot speak, and is severely retarded. He requires 24 hour, awake supervision. He is mobile,, and has no concept of danger. He is content and safe in his home there.

89. I feel that community-based facilities are good for some individuals but should be decided on an individual basis, not one size fits all theory.

90. That care for this vulnerable population isn't one size fits all.

91. ICF residents have access to higher quality services and opportunities for training and community involvement.

92. One size does not fit all. Just like services for elderly - Independent Living, Assisted Living, Nursing home, same choices need to be available to mentally disabled.

93. Not all individuals are able to function in the community, not all communities want them or are prepared for them; others should not be making this decision for us, and we feel that my sister is best served in her current setting. She has thrived in her ICF and has access to any and all services she may need. The staff is well trained and caring and has her best interest at heart. She would not receive the quality care she does if she were in a different setting. My parents went through the legal system to have my sister admitted to her ICF when she was four years old and now the government is completely disregarding that court ruling. The move to de-institutionalize has created so much unnecessary stress and heartache for so many families who know what is best for their loved one.

94. Community may be good for the higher functioning, but there is very little oversight and support in the community. The residents at ███ have more involvement in the community than residents in smaller settings or nursing homes. care is by far inferior to the care at the █████ centers in ██.

95. Smaller settings are dangerous because many of them lack supervision, accidents can happen anywhere but when staffing ratios are minimal and supervisors are miles and miles away the chances and opportunities for injury an abuse increase.

96. There are vulnerable individuals who would not do well in a community living. ICF/NF have trained, staff with all the skilled services right on campus. These staff members have longevity of service which is indispensable.

97. My daughter is a 47 year old with the mind of a 15 month old. She would not be able to function in a community-based facility. I know this because my son and a niece both have worked in community-based facilities. My daughter cannot tell what she wants to eat, nor can she handle money. She is mentally 15 months old, and she has no speech. She cannot tell a person when or where she is hurting. She cannot operate a range, get a drink from the refrigerator or water fountain. She cannot make decisions for herself. █████ Center is the best facility for her. She absolutely could not survive in a community-based facility. If she could, I would have her home with me.

98. The current ICF facility is the most appropriate setting for my daughter, █████.

99. YES! ONE SIZE DOES NOT FIT ALL. CILA'S ARE FINE FOR SOME BUT NOT ALL!

100. The community is not ready to support everyone. The people in the community are not ready to accept the physically and mentally disabled. The community is not the safest place to be even for people who are capable of taking care of themselves. The Olmstead decision guarantees choice for people - to live in the community or to live in an ICF/ID.

101. My daughter receives excellent care and has a full well-rounded life. She is safe and happy! A setting that is designed for specific people doesn't mean they are isolated. It enhances their life.

102. One size does not fit all.

103. Many Intellectually disabled persons have multiple disabilities. Often community based care is unable to care for them, and at times the small community facility asks they be returned to the ICF. Also, some states impose, "Money Follows the Individual", so that, when they depart for a small residential placement, the ICF loses the funding for that bed. If the individual returns to the ICF because the small group home is incapable of caring for the person, the funds don't return to the ICF. I know of one individual who has departed twice causing the ICF to lose funding for beds on two occasions. Each time the small community facility was incapable of caring for the resident.

104. It would take away needed care and services and cause my brother to regress.

105. I would like them to know that moving residents out of institutions like ██████ developmental Center does not always work out for the benefit and safety of the individual.

106. No one size fits all. These laws have made an exceptional like facility like ██████████ Dev. Center slowly force out residents who wanted to stay and families wanted them to stay. We were lucky to be able to move to another State run community home cottage nearby which has excellent care, but we know others who have not been so lucky. Good institutions can be the best care for some handicapped persons and they deserve to have this available. Institutions for our college students and normal kids do not have the negative connotation that institutional facilities do for the retarded. Sometimes, comprehensive, shared resources are the best and the cheapest. We think ████ was once the best of the best and should have been supported to remain strong and comprehensive. Freedom of choice should be the option based on eval of Drs, Family, caretakers, and resident (if competent).

107. Licensing should be a priority, back ground checks, no one involved in the government making decisions should be allowed to own or profit from a small community-based facilities. Training of staff is a necessity along with a pay scale that is competitive with today's market to alleviate high turnover rates. Why should someone get paid the same as McDonald's employees to take care of those with disabilities who need the security of a familiar direct care staff member. If the pay was high enough, the direct care staff would not have a high turnover rate. This should be a career opportunity and not a stepping stone to a higher paying job.

108. Individuals who are profoundly challenged mentally and have behavioral disorders require constant supervision by staff trained to accommodate their needs. They require structure.

109. This move does not meet the needs of all of its clients. Therefore I am opposed to a "one size fits all" approach. Many clients need the full range of services that an institution needs. Also I am distressed by the degree of underutilization of facilities currently available in our institution, while great amounts of resources go into constructing new community buildings and other facilities.

110. There is a fierce national debate regarding models of care appropriate for individuals with disabilities who require long-term care. Debate participants whose family members have profound cognitive - developmental disabilities (those unable to work, unable to report their hurts and needs) are vastly out-numbered by other debate participants, those with physical disabilities (who possess the skills to "self-advocate"), those with age - related disabilities (who also can often self-advocate) and a myriad of other participants, including younger families (who are presently able to provide the majority of the care required by their family members with disabilities) and also representatives of organization and businesses who have clear conflicts of interest in their advocacy work. It is critical that members of Congress have an understanding of the debate issues (including whether federal agencies should fund programs which contribute to the elimination of congregate care/the institutional model). Congress should work to have an understanding of the different debate participants. Good public policies should be based on experience, common sense and humanity. There should be deference and respect for the positions of families who have first-hand experience in the care and treatment of persons with life-long disabilities.

111. A lot of these residents may not adapt well to a drastic change in their environment.

112. All mentally retarded people are different and all need different types of living arrangements and care. Some can do well in community, others need more help.

113. We don’t feel the small community based facilities provide anywhere near the services, activities of medical services that the ICF's provide. The ICF's have well trained staff and adequate supervision that is lacking in the community. Residents at ICF's are protected on grounds and not subject to the dangers of living in the community.

114. She has been at the ICF since 1981 and she is very happy there. She would be totally disorientated if moved to a smaller community based facility.

115. Our son was living in a community home he was about 20 yrs old. The house parents were not trained for the job. They used some of the other clients to do the job of caring for the other

clients. My son was injured when another client was mowing the grass and he ran the mower over my son’s foot. The hospital surgeon managed to save my sons foot.

116. As a nurse in [redacted], residents in community settings have constant turnover in care. Incidents of negligence & abuse have occurred in some throughout the state but have managed to be downplayed. Govt needs to take a closer look @ those on the streets, shelters & jails. Like in CA & NY after closing ICF's these souls are cast out eventually succumbing to life threatening situations & sometimes death.

117. Some individuals cannot be served to the greatest needs required for simple survival if ICF funding & facilities are reduces or patients/clients cannot have access. Well managed ICF's provide a continuum of care that our less fortunate citizens need and serve.

118. He could not be in any other institution because he wouldn't get the care as he does at [redacted] [redacted]

119. Not in agreement. Not all are equipped to live in a community setting with the proper care and level of skilled care to meet their needs

120. Lack of access to medical and dental needs

121. needs 24 hour care to move her at her age would be devastating

122. I have made my feelings known to the State. I feel certain individuals benefit from a developmental center in the state of [redacted]

123. We are emphatically opposed to de institutionalizing all ICF residents. Some such as our daughter cannot function in a community living setting. She needs the services provided on campus of an institution such as medical, physical, occupational etc and needs constant 24 hr supervision and support. We tried a community based facility for 1 1/2 years and it set her back so far that when she returned to [redacted], she was in worse shape physically, mentally & behaviorally than she'd been when she first went to the community. There is a need for both types of facilities depending on the needs of the individuals.

124. My daughter gets incredible 24 hour care in the current ICF residence They keep close watch and daily clean & change catheter. She gets constant inspections to prevent bed sores. She is served by caring trained individuals who respect her many needs. Small community based facility simply unable to keep up with her many needs. Sending her to community facility would significantly shorten [redacted]'s life span

125. [redacted] has resided in [redacted] since the age of 7, has had all his need met by a wonderful staff all thru the years. He does need 24 hour supervision, takes meds for seizures, etc

126. IFC's need to remain open for individuals such as my dear brother as a community setting wouldn't be acceptable. The gov't needs to understand that individuals like my brother are born every day and need access to ICF's

127. We are forever pleased to hear our daughter

128. Don’t mess with something that works

129. Family member passed away at ██████ DC 4 years ago. He received excellent care for 30 years.

130. Community sites as they currently exist &/or funded &/or regulated are not safe for MR persons with extreme disabilities. We need both types of facilities. The need for both is going to increase as the baby boomers age and are unable to care for children still at home

131. The facilities & equipment needed for my daughter are a few and large. The facilities are on one floor and equipment is stored out of the way. She shares the dorm with other girls with similar problems. ████ is happy and well taken care of by competent staff 24/7

132. Some clients do better in a large facility where you can be sure of adequate help and a variety of activities and medical care. Her DRs come to ██████████. She is transported to the training center for her classroom and other therapies. She gets wonderful care and we see her every month.

133. We don't consider our daughter institutionalized. █████ is her home and she prefers to be there with her friends It isn't fair of unknowing people to think they should make decisions for us

134. We need all services not just one type

135. People with severe disabilities require ICF care because they cannot function independently

136. Community based facilities are operated for profit. The biggest problem with them is the lack of court sponsored supervision of the direct care staff, many of whom are not well trained’

137. Our govt does know. We are encouraging our state legislators to reverse the decision to close our ICF's in ██. We are hopeful because there are currently no facilities to provide the same level of care in █████████████

138. No local small facilities have a physician present in house 24 hrs a day 7 days a week. None provide annual review with all his multiple caregivers, therapists etc. present at the same time. When such services of this quality are available locally can consider deinstitutionalization

139. Community not suitable for someone at the profound level of retardation

140. Our daughter is very well served in her 16 bed ICFDD. I like that it's 8 men and 8 women. The group gets along very well. I do not want our daughter moved at this time

141. Very much against it, my brother has severe disabilities and no group home we visited would be safe for him. He suffers from pica and puts everything into his mouth, must be supervised closely. Group homes are fine for the less-severe disabled with less serious medical health issues but one solution does NOT fit all.

142. The ICF/IID setting trains professionals from all clinical fields in the special treatment needs and approaches for individuals with developmental disabilities. From there they are ready to serve in many settings, including more "inclusive" settings where the numbers of IID may be small. Without these facility-based centers, the quality of training in the U/S/ is reduced, even to the point of dangerous shortages of specialists properly trained and qualified.

143. I am not aware of any small community based facilities in our area. I mainly want the gov't to know that many handicapped citizens cannot be kept safe in a private home setting.

144. ICF residents have a safe protected environment in which to live with freedom in a safe place.

145. We are pleased with our daughter in a smaller group home. She is happy.

146. OK if can furnish all of the above.

147. For those that need/qualify for ICF care, community care is less intense and in line with there needs as knowing professional are and centers of training are. The same level and quality of care costs more for these individuals in the community as there are no benefits of costs for centralization providing less care for high need individuals may then to lower quality of and increased mortality and.

148. We should either legislate euthanasia in America or fund ICF/IDD or IID facilities. My word is very unsafe in a typical home. He does not form relationships with peers and requires extraordinary supervision to even travel in a community setting. Inclusion is neither meaningful nor safe. He has complex medical problems and would be unsafe as well in a community-based residential program. Even among people with disabilities, he is in a minority of severely impaired individuals.

149. Do not close the facility.

150. My son has lived in his ICF home for 30 years. He feels very secure there. He has insecurities because of being placed in facilities in an effort to find help for him when he was young. He

would be devastated if he moved from his home of 30 years. He gets to have short home visits. My husband died 11 years ago and my health is failing. My greatest fear is that he may be moved after I am gone. He need the ICF setting. He is a wonderful son.

151. I feel there is no one answer fits all. My daughter has lived at home with me in a group home and at ████. She has been happiest at the ████. I am 80 and therefore could not totally care for her and I found group homes just don't have the needed medical services my daughter needs. My daughter cannot handle money, dressing properly, toilet needs, food prep. ect. She could never survive on her own.

152. I think the idea is unreasonable. When one has parents almost 80 years old, there needs to be a place where one's care can be almost guaranteed. Small community-based homes in this state do not provide that kind of care. We tried twice for care in a c/b home and could find NOTHING that came close to his care in our IDD centers.

153. Our daughter was in a group home for a number of years as her conditioned worsened they were unable to meet her needs and asked that she be removed from their care. She has a rare degenerative syndrome, therefore community placement is inappropriate.

154. We were able to keep ████ home for 18 years: we are able to bring her home for one or two days at Christmas & Birthday: We visit her about every two or three weeks. ████'s mother has dement PPA & it is progressing to the extent she cannot cook, & other activities. Pray for us. ████████.

155. One size doesn't fit all situations. Small homes will have problems of staff absences despite plans in place to counter this. Resident/staff will be. Not good for severely retarded or medically needy residents.

156. He placed ████ in the community a few years ago. It was closer and we could visit more often. He was there three months and we rushed him back to █████. He was sent to the hospital intensive care unit. He is fine now.

157. My son lived in several group home but it didn't work out for him. I told Dick Durbin that my son's needs were best met by ICF.

158. With certainty, our son would not be able to function in a smaller group home.

159. My daughter is in one excellent place. She can go in her wheel chair an that all. She has been in state facilities for almost 60 years. She is the best one of all. Good staff-well run-lots of things to do for residents. I hope she stays at ██ Development.

160. lived at the Human Developmental Center at the for most of his life when the center and cooperated in the housing- now runs the house where he lives with a house mate and full time caretakers he works at a sheltered workshop challenges-He does not talk but understands & responds to what is said to him- he is very happy in this living situation.

161. I always thought that my child would be in the home he was use too. But now I see what is happ I don’t what to think at this time in my life(at my age & also with the loss of my husband & grandchild (the I use to have is almost gone- some of the questions from the state and I don't know.

162. While smaller group homes are fine for higher-functioning individuals, for those with profound problems (like my brother) the ICF offers the least restrictive environment for leading a safe, productive life. Unlike in many smaller group homes, the community around is very supportive of the individuals and many in the community work at as well, leading to more community involvements because of this and other factors, my brother has far more opportunities for activities(see #8&9) then he would in a non-ICF environment.

163. Complete de-institutionalization and/or privatization of ICF resident care is a betrayal of government responsibility to protect the most vulnerable. ICF should be maintained as an alternative for those individuals/families who cannot benefit from small group or community-based facilities.

164. Yes. provides the full spectrum of care and housing for disabled persons, including community living facilities. My son could probably live "off-campus" with close supervision.

165. Our son had seizures real bad, now he hasn't had any since 2013 and only on, his seizures was grand mall. He has a DR and nurse on campus that has helped him also. They (nurse gives him his medication & checks them every day. She would not get that anywhere in community. He use to run off a lot. Never runs anymore & seems very happy & doing great. I do not want him anywhere else, he is doing great.

166. Please do not de-institutionalize

167. moving residents with high level medical needs and no(or limited) self-care skills/communication skills places the resident at a great risk. It additionally places the community members at risk due to limited functioning and potential to create risky living situations.

168. Community based setting ok for some, Not for profound IDD.

169. We (parents, siblings, ect0 favor our son's continued residence @ Dev. Ctr vs. Group Home. He is entirely dependent on others for his most basic needs. Physiological- Food

according to his diet plan, dietician monitors reviews deviances ect. Safety needs- The steady personnel know personally of his challenging behaviors and plan staff attends ongoing training; reliable employment benefits, and is dedicated. Belonging- Respected as to his "developmental disabilities". Esteem- Confidence in staff and self when he accomplishes a goal as to his profile, re: IHP Self-Actualization- Stall knows his level of needs his full potential and the realization of that potential.

170. Yes! I'd like the Government to know my son tried a small community based facility and that is where his behavior got out of his control. Since he can't understand most speech, he cannot converse with others, read, or understand TV, his only way to pass time is workshop or his ability to walk all over the large campus.

171. This is a backward movement. One size doesn't fit all. People will suffer. And they will disappear which will please those in power. (The government would rather kill people rather that save them. It's cheaper.)\

172. My son would not receive adequate care at a small community-based facility, It would not have the same resources.

173. Horrible idea!! Would not work for. ████ is our salvation. Life would not be manageable for our family without it. ████, MD.

174. I believe it is financially motivated. People who don't think ICF's are right for their loved ones wish to force their choices on us rather that allow us to do what we think is best for ours. Also, I believe there is a concerted effort to keep the option of an ICF not offered to those who are just now looking for services and placements.

175. The level of support at the ICF is tremendous. In addition, any move to another facility would be traumatic to this individual. I don't believe the level of medical care, social interaction, or mental stimulation would be the same outside of the ICF.

176. Smaller community based facilities could not provide continuity of care my son needs because of the following disabilities suffered at birth: severe mental retardation, seizures, physical impairments (no speech, wheelchair needed), behavior challenges, ongoing medical concerns.

177. As parents we are much against this as we were forced to place our son in residential care since we could no longer provide what he needed at age of 14 yrs. In the prospect is four men of his level in the care of two people. That would be life threatening and insane to even consider! These people NEED the large staff that ████ provides!!

178. My severely handicapped son is much better served by living at the ████ Resource Center than living in a small group home.

179. Yes I would. It should be based on the individual and their disability.

180. As for equal or better care in any IDD residence concern that other facilities lack long term, experienced staff, nurses or doctors

181. Many need a very structured environment 24/7 and a well trained and stable longevity direct care staff who plan to make it their career. It takes a special person to work with those needing ICF care. Turnover by staff in group homes high & drugs used to control behavior. Medical care more problematical in community settings. ICF's have doctors & nurses on staff.

182. Object to taxpayers funding for groups whose sole agenda appears to be to empty all congregate ICF/IID's. For those with very acute cases, it is a near insult" Years ago, a trusted group home operator dismissed our son, recommending our current ICF/UUD, where surgical remedial work resulted in improved coordination and ultimately to supported employment at a sealy mattress factory. Medical and dental care (onsite) in my observation cannot be met, much less exceeded, at a group home for our type case. That said, many group homes excel at caring for milder cases of IID.

183. A "one size fits all" solution just is wrong. Higher functioning individuals may do "better" in small settings but they would do even better if they had the special services and activities of a larger facility/institution nearby.

184. It is a mistake!

185. Now many families are VOR members-including our administrator.

186. When a closure of the Center was threatened in 1995, we like other guardians sought out private provider group homes in this area for our son. All four of the providers we contacted ruled our son as unable to function in their type of group home. We also found over the years that the various studies purporting the great advantages of community placement were funded by or supported partially or wholly by organizations that were the drum-beaters for deinstitutionalization. People like the Center almost never were approached for our opinions for obvious reasons.

187. Do not de-institutionalize. My child is best served in the institution where she currently resides. is an outstanding residence for all!!

188. Small community based facilities do not have sufficient medical, dental, recreation, vocational, transportation and nurses on duty 24/7.

189. I have a good example: I kept my son until he 16 years old and then placed him. He is happier. Rather have him in STS that a group home. I have visited group homes too happy what I saw.

190. It's cruel plain thoughtless to uproot people with limited understanding from the life they're known for so many years & subject them to a major life stress that a move involves. To remove them from the voices, sounds & smells that are lifelines to their feeling of security & belonging is unimaginable! If it ain't broke-don't fix it" - & [redacted] Center 'aint' broke!

191. My son is at home at [redacted]. His disabilities are sever and cannot function in a residential setting. [redacted] is the best facility to meet all of his needs-including safety concerns. He requires 24 HR care in a monitored setting.

192. I am adamantly opposed to it- my daughter is healthy & happy in here. She is non-verbal & would be able to defend herself against others-I do not believe she would survive-Please do not do it.

193. Deinstitutionalization is a rigid agenda without unbiased consideration for DD persons' own needs and preferences. It has little respect for family/guardian input, thus jeopardizes the time tested quality care the disabled person may be currently benefiting at an ICF in favor of high risk in very small community based living environment.

194. See attached, community-based facilities are not appropriate for most of the ICF residents, especially my brother. The safe monitored Human Development Center where he lives provides him the ability to socialize with others which is very important and necessary for him. His medical needs are addressed by an onsite physician and his care is overseen by skilled personnel. We try to have him home one weekend a month but when we take him back he walks in announcing "I'm home." I also cannot understand the justification of this policy favoring deinstitutionalization of these much needed facilities.

195. My brother resides in a beautiful, clean facility with a very caring staff. He loves his home there and the people who care for him. They stay in touch with family and if we have any concerns- they address it right away. He gets good medical care and is ongoing individual programs to help him grow educationally, personally, physically-very well rounded. My brother needs constant aide and supervision. He gets it there!

196. First of all- I do not think of [redacted] as an institution, [redacted] is a place where residents are in groups of four to six. In different units comprising of a kitchen, dining room, living/TV room, and bedrooms having one (usually in some units) resident to a bedroom. It is stress by the supt on down that these units are the residents homes and are to be treated that way. Before govt officials enact laws concerning ICFs, they need and should spend time at least a couple of days. Also, our Govt. should meet and discuss with direct family/guardians of the residents before any law/decree given affecting ICF's! (attachment)

197. My comments on this subject are contained in the attached letter, sent to a state senator 20 years ago, I still consider them valid.

198. My daughter has lived at ███ for 45 yrs with superb medical and daily living care. Her life would be in jeopardy without 24/7 medical oversight, and moving her after adjusting to a lifetime at her home. I believe an ICF, a medicaid facility must "maximize ones potential and prevent regression as the law states!

199. My brother has been a resident of ██████████ since 1994 after the death of our father. I have been involved with ████████ for many years. As my brother's plenary guardian, I attend all of his quarterly reviews and can vouch for the professionalism shown at all levels of care. Case Mgr., nursing, occupational therapy ect, The state of █. (DMR) is demanding through the standards they set and I am comforted to know my brother is well cared for.

200. My daughter is well-taken care of at █████████ Developmental Center and I wish she could stay there; however Gov ██████ is for closing all institutions. Please help to keep this facility open.

201. Community homes work for some individuals some need institutional care the home my son is perfect for him.

202. There are dangers in the community there are always dangers about funding being cut for community programs lack of dentists who specialize in mr plus a lack of medicaid funding for adults there is a greater chance of physical, mental, and sexual abuse going undetected.

203. I have supported VOR for many years, but question it's connection to ARC whose mission has been deinstitutionalization. Please continue you vital work.

204. There are some individuals who need the supervision & care of an institution and if they do have it they could come to harm or harm others. But an institution provides the services to give them the best life under the circumstances. I would vote as a ballot and taxes to provide this care.

205. ICF residents are able to have coverage of care support from other co in case of emergency coverage activities available in cottage and on grounds medical care on grounds if needed. Always someone trained in need of residents avail. on grounds, Physical one level for all residents no direct care staff know needs and habits of residents. All necessary staff &S programs on grounds-no duplication out in community for medical programs, staff, etc.