By: Representative Evans

To: Public Health and Welfare; Appropriations

HOUSE BILL NO. 929

AN ACT TO CREATE AND EXPAND HOME-BASED LONG-TERM CARE SUPPORT SERVICES FOR INDIVIDUALS WITH DISABILITIES AND THE FAMILIES OF THOSE INDIVIDUALS; TO PROVIDE DEFINITIONS; TO PROVIDE PRINCIPLES FOR THE HOME-BASED LONG-TERM CARE SUPPORT SERVICES; TO PROVIDE MINIMUM STANDARDS FOR THE HOME-BASED LONG-TERM CARE SUPPORT 3 4 5 SERVICES; TO PROVIDE A SCHEDULE FOR CREATING AND EXPANDING 6 SUFFICIENT HOME-BASED LONG-TERM CARE SUPPORT SERVICES; AND FOR 7 8 RELATED PURPOSES. BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MISSISSIPPI: 9 SECTION 1. To conform with the U.S. Supreme Court decision 10 in Olmstead v. L.C. 527 U.S.581, 119S.Ct.2176, 144L.Ed.2d (1999), 11 the State of Mississippi commits to provide sufficient home-based 12 long-term care service options to persons with disabilities and 13 families that include members who are persons with disabilities. 14 The effort is intended to expand opportunities for persons with 15 disabilities to receive services in the most integrated setting 16 appropriate to their needs and, by so doing, to empower those 17 18 citizens to have a higher quality of life by being more independent in their communities and avoiding institutional 19 placement. The effort will be accomplished by (a) redirecting 20 existing long-term care dollars and/or developing new long-term 21 care dollars and (b) redesigning regulations to encourage 22 home-based individual and family support services in lieu of 23 institutional services that conform to principles ensuring 24 25 consumer-control, choice of service models, availability to eligible recipients and eligibility based on functional needs, not 26 medical diagnosis, type of disability or age. This effort is 27 28 based on the premise that recipients who so desire should be able to avoid nursing home and other institutional placement and choose 29

their own preferred mode of noninstitutional long-term care.

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- 31 SECTION 2. The following definitions shall apply to this
- 32 act:
- 33 (a) "Activities of daily living (A.D.L.s)" means
- 34 personal care activities that are routinely part of daily living,
- 35 including, but not limited to: eating, toileting, dressing,
- 36 grooming, personal hygiene, bathing and transferring.
- 37 (b) "Agency" or "agencies" means any and all state
- 38 agencies that provide long-term care support services to persons
- 39 with disabilities and their families now or in the future.
- 40 (c) "Consumer" means an individual with a disability of
- 41 any age who needs or uses support services.
- 42 (d) "Consumer-directed" means a mode of service
- 43 delivery that gives the recipient of individual and family support
- 44 services (the consumer) maximum control to select and manage his
- 45 or her own service plan. This is the preferred mode of service
- 46 delivery.
- (e) "Disability" means a severe chronic cognitive,
- 48 psychiatric, emotional, sensory and/or physical disability of a
- 49 person that:
- 50 (i) Limits ability to perform one or more
- 51 activities of daily living (A.D.L.s); or
- 52 (ii) Limits ability to perform at least two (2)
- instrumental activities of daily living (I.A.D.L.s); and
- 54 (iii) Requires substantial supervision, episodic
- or short-term crisis assistance; and
- 56 (iv) Needs assistance with the performance of
- 57 health-related tasks; or
- (v) (A child under the age of six (6) who is at
- 59 risk of developing a disability. A child is determined to be at
- 60 risk if the child has substantial developmental delay or specific
- 61 congenital or acquired condition that has a high probability of
- 62 resulting in a developmental disability if services are not
- 63 provided.)

| 64 | (f) "Family" means the person or persons with whom the |
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| 65 | person with a disability resides and who are primarily responsible |
| 66 | for the physical care, health and nurturing of the individual with |
| 67 | a disability. The term does not include hospitals, sanitariums, |

68 nursing homes, group homes, or any other similar institution.

(g) "Financial assistance" means a monetary payment to an eligible person with a disability or the family of a person with a disability needed to defray the cost of support services related to the disability. Financial assistance includes, but is not limited to, cash subsidies, cash allowances, cash vouchers or reimbursement to enable eligible persons to acquire support services.

(h) "Functional need" means the need for personal assistance based on abilities and limitations of individual consumer, regardless of age, medical diagnosis, or other category of disability.

80 (i) (i) "Individual and family support services" means 81 goods, services and financial assistance to an individual with a 82 disability or the family of such an individual that are provided 83 to meet the goals of:

1. Providing a quality of life comparable to that of similarly situated individuals not having a disability and families not having an individual with a disability; and

2. Preventing premature or inappropriate out-of-home placement.

(ii) Individual and family support services include, but are not limited to, the following:

1. Communication services.

Parent education and training.

3. Counseling services.

4. Crisis intervention.

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| 96 | 6. Dental and medical care that are not |
| 97 | otherwise covered. |
| 98 | 7. Equipment and supplies and other assistive |
| 99 | technology. |
| 100 | 8. Financial assistance. |
| 101 | 9. Home and vehicle modifications. |
| 102 | 10. Home health services. |
| 103 | 11. Homemaker services. |
| 104 | 12. Parent education and training. |
| 105 | 13. Personal assistance services. |
| 106 | 14. Recreation. |
| 107 | 15. Respite care. |
| 108 | 16. Self-advocacy training. |
| 109 | 17. Service coordination. |
| 110 | 18. Specialized diagnosis and evaluation. |
| 111 | 19. Specialized nutrition and clothing. |
| 112 | 20. Specified utility costs. |
| 113 | 21. Therapeutic and nursing services. |
| 114 | 22. Transportation. |
| 115 | 23. Vocational and employment supports. |
| 116 | (j) "Instrumental activities of daily living |
| 117 | (I.A.D.L.s)" means activities that support the activities of daily |
| 118 | living, including, but not limited to: taking medications, |
| 119 | managing money, preparing meals, shopping, child care, light |
| 120 | housekeeping, using the telephone, or getting around the |
| 121 | community. |
| 122 | (k) "Program" means the effort to create and expand |
| 123 | long-term care service options established and committed to in |
| 124 | Section 1 of this act. |
| 125 | SECTION 3. The following principles shall be adhered to in |
| 126 | the development and ongoing management of the program: |
| 107 | (a) Individuals with disabilities and their families |

Individuals with disabilities and their families

are best able to determine their own needs and should be empowered

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(a)

H. B. No. 929 01/HR12/R1214 PAGE 4 (RF\DO)

- 129 to make decisions concerning necessary, desirable, and appropriate
- 130 services.
- 131 (b) Individuals with disabilities should receive the
- 132 support necessary for them to live as independently as possible at
- 133 home if they choose.
- 134 (c) Family support should be responsive to the needs of
- 135 the entire family unit.
- 136 (d) Supports should be sensitive to the unique needs
- 137 and strengths of individuals and families.
- (e) Supports should build on existing social networks
- 139 and natural sources of support.
- 140 (f) Supports will usually be needed throughout the
- 141 life-span of the individual who has a disability.
- 142 (g) Supports should encourage the integration of people
- 143 with disabilities into the community as much as possible and when
- 144 the consumer prefers that integration.
- (h) Support services should be flexible enough to
- 146 accommodate unique needs of individuals and families as they
- 147 evolve over time.
- 148 (i) Support services should be consistent with the
- 149 cultural preferences and orientations of individuals and families.
- 150 (j) Support services should be comprehensive and
- 151 coordinated across the agencies that provide resources and
- 152 services, or both, to individuals and families.
- 153 (k) Individual and family home-based support services
- 154 should be based on the principles for sharing ordinary places,
- 155 developing meaningful relationships, learning things that are
- 156 useful, and making choices, as well as increasing the self-esteem
- 157 and status, and enhancing the reputation of the individuals
- 158 served.
- 159 (1) Supports should be developed and expanded in the
- 160 state that are necessary, desirable, and appropriate to support
- 161 individuals and families.

- 162 (m) The policies of the program should enhance the 163 development of the individual with a disability and the family.
- (n) A comprehensive, coordinated system of supports to families effectively uses existing resources and minimizes gaps in supports to families and individuals in all areas of the state.
- (o) Service coordination is a goal-oriented process for coordination of the range of services needed and wanted by persons with disabilities and their families, and is independent of service provision.
- 171 (p) No resident who wishes to remain in an
 172 institutional setting will be forced to receive support services
 173 in a noninstitutional or home-based setting.
- SECTION 4. (1) All home-based individual and family support service providers through or by the agency or agencies shall meet the following minimum standards:
- 177 (a) To the maximum extent possible, consumers who so
 178 desire shall select, manage, and control their individual and
 179 family support services.
- 180 (b) Eligibility shall be based on functional needs, not 181 medical diagnosis, type of disability, or age.
- 182 (c) Options for services will be available in the
 183 individuals= and families= homes and other independent living
 184 environments including, but not limited to, school, work, and
 185 recreational settings.
- (d) The service system shall be capable of providing individual and family support services twenty-four (24) hours a day, seven (7) days a week, and, when necessary, provide back-up and emergency services.
- (e) Co-payments and cost-sharing will be required of individuals and families whose adjusted gross incomes exceed two hundred twenty-five percent (225%) of the federal poverty level.
- 193 However, co-payments and cost-sharing requirements will be
- 194 structured so that they are not a disincentive to participation.

- Each consumer's program of services will be based 195 upon a mutually-agreed upon individual service plan jointly 196 developed by the individual or family and the provider-agency. 197 198 The individual or family will be given an opportunity to choose 199 between different service delivery options including vouchers, consumer-directed individual provider models, and 200 consumer-directed agency models. To the maximum extent possible, 201 consumers will be able to select and to hire whomever they choose 202 203 as personal assistants, including family members.
- 204 (g) Consumers will be offered training on how to manage 205 and coordinate their service program (e.g., select and dismiss 206 their support service provider, financial management).
- 207 (h) All providers of individual and family support
 208 services shall assure that consumers are fully informed of and
 209 accorded their rights and options with respect to selecting,
 210 managing, and changing their service providers and their rights to
 211 privacy and confidentiality. Consumers who are dissatisfied with
 212 their services have the right of appeal to the appropriate agency
 213 governing board.
- (i) All persons providing personal assistance shall be
 paid at least one hundred fifty percent (150%) of the federal
 minimum wage or a comparable daily rate and be offered health
 insurance and other benefits.
- (2) Eligibility for individual and family support services under this act shall be for persons of all ages who have a disability as defined in Section 2.
- 221 (3) A comprehensive assessment of support service needs
 222 shall be made for each applicant to determine eligibility for
 223 services and the applicant's ability to perform each activity of
 224 daily living and each instrumental activity of daily living. The
 225 applicant=s self-evaluation of his or her needs and abilities, or
 226 the applicant=s formal representative=s evaluation of his or her
 227 needs, shall be an integral part of this assessment.

- 228 (4) The Division of Medicaid shall establish a uniform
 229 instrument to assess eligibility for individual and family support
 230 services.
- (5) The consumer or, where appropriate, their family have the right to acquire the assessment from any public or private source that conducts the assessments.
- 234 SECTION 5. (1) The State of Mississippi will create and
 235 expand home-based long-term care service opportunities so that, by
 236 June 30, 2009, every person with a disability who is currently
 237 using, or who is in need of, long-term care support services will
 238 have the option of receiving those services in a home-based
 239 setting. The conversion of the current system, and the creation
 240 of the additional options, shall be in compliance with the
- 242 (a) By June 30, 2002, at least twelve and one-half 243 percent (12.5%) of the total number of persons with disabilities 244 in need of long-term care support services will be given the 245 opportunity to have those services provided in-home;
- (b) By June 30, 2003, at least twenty-five percent (25%) of the total number of persons with disabilities in need of long-term care support services will be given the opportunity to have those services provided in-home;
- (c) By June 30, 2004, at least thirty-seven and one-half percent (37.5%) of the total number of persons with disabilities in need of long-term care support services will be given the opportunity to have those services provided in-home;
- (d) By June 30, 2005, at least fifty percent (50%) of the total number of persons with disabilities in need of long-term care support services will be given the opportunity to have those services provided in-home;
- (e) By June 30, 2006, at least sixty-two and one-half percent (62.5%) of the total number of persons with disabilities

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following schedule:

- 260 in need of long-term care support services will be given the
- 261 opportunity to have those services provided in-home;
- 262 (f) By June 30, 2007, at least seventy-five percent
- 263 (75%) of the total number of persons with disabilities in need of
- long-term care support services will be given the opportunity to
- 265 have those services provided in-home;
- 266 (g) By June 30, 2008, at least eighty-seven and
- 267 one-half percent (87.5%) of the total number of persons with
- 268 disabilities in need of long-term care support services will be
- 269 given the opportunity to have those services provided in-home;
- 270 (h) By June 30, 2009, one hundred percent (100%) of the
- 271 total number of persons with disabilities in need of long-term
- 272 care support services will be given the opportunity to have those
- 273 services provided in-home.
- 274 (2) Funding to accomplish these objectives will be acquired
- 275 through the appropriation of new dollars and the conversion of
- 276 dollars currently being appropriated for institutional long-term
- 277 care.
- 278 (3) No conversion of funding mentioned in subsection (2) of
- 279 this section will force any consumer to leave an institution
- 280 against his or her will or be deprived of institutional care as an
- 281 option.
- SECTION 6. This act shall take effect and be in force from
- 283 and after July 1, 2001.