

Effect of Residence on Receipt of Preventive Care by Adults with Mental
Retardation/Developmental Disabilities

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III. Background

Mental retardation in history

“Mental retardation is an idea, a condition, a syndrome, a symptom, and a source of pain and bewilderment to many families” (Biasini F.J., Grupe L., Huffman L., et al., 2008) and it has been around as long as the genus *homo sapiens*. The first mention of the concept of mental retardation can be found as far back in history as in ancient Egypt around 1500 B.C. How people with mental retardation were treated, however, varied throughout history. For a very brief summary of early history of treatment of the mentally retarded/developmentally disabled, see Appendix 1.

Prior to the second part of the 20th century, most of the people with mental retardation/developmental disabilities in U.S. lived in state institutions. Reports of abuse and maltreatment were rife. As a result of disillusionment with residential treatment and wide reports of abuse in residential centers, advocacy groups began to be established in the U.S. in the 1950's. These groups campaigned for community-based residential and treatment options. Beginning with the landmark law suit in Pennsylvania (the Wyatt-Stickney federal court action) in the 1970's which established the right to treatment of individuals living in residential facilities and defined purely custodial care as unacceptable (Biasini F.J., Grupe L., Huffman L., et al., 2008), and the 1977 ruling by U.S. District Judge Raymond Broderick that keeping people with mental retardation in institutions was a violation of their constitutional rights, a number of similar suits were filed across the country and brought the concept of deinstitutionalization to the forefront (Cooke, V., 2008). A very important lawsuit (the first of its kind) - Pennhurst State School and Hospital vs. Haldermann - was brought in 1986 by a former resident of an

institution and asserted that people with mental retardation had a right to habitation and a right to treatment in the least restrictive environment and that Pennhurst was not fulfilling those rights.

The ICF (Intermediate Care Facilities) program began in 1971, but it wasn't until 1974 that the federal government initiated certification of ICF/MRs (Intermediate Care Facilities for the Mentally Retarded) for 4-15 persons and specified how they should be staffed to satisfy the requirements. These facilities, from very small (4 residents) to very large became a major component of community service systems in many states.

The other major Medicaid program for long-term care for individuals with mental retardation and related conditions, the Home and Community-Based Services (HCBS) Waiver, was authorized under the auspices of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35). The HCBS Waiver allowed states to provide home and community-based services for persons with a diagnosis of mental retardation or related conditions who would otherwise require the level of care and services provided in an ICF/MR. Centers for Medicare and Medicaid Services (CMS), formerly Health Care Financing Administration (HCFA) also allowed states to apply for 5-year renewal periods for their waivers, simplifying the application procedures for such renewals.

The HCBS Waiver itself pays specifically for community and home-based long-term care services for persons with mental retardation and related conditions, with regular Medicaid state plan covering their medical services. It provides supports necessary for persons to be integrated and included in their communities. Even if consumers reside with family caregivers, they can still receive HCBS Waiver services, such as family support, assistive technology, and transportation. In 2002 all fifty states and the District

of Columbia had instituted HCBS Waiver services for people with mental retardation and related conditions, and Federal Waiver spending in the U.S. grew to \$7.2 billion. By 2007 the spending grew to \$11.4 billion. The HCBS Waiver in 2002 constituted 48% and in 2007 63% of all federal Medicaid reimbursement for spending for long-term care of persons with mental retardation and related conditions in the U.S. (Braddock D., Hemp R., Rizzolo M.C., 2004). In 1998, two thirds of the participants in Medicaid programs for persons with mental retardation and related conditions were funded by HCBS Waiver programs and lived in some form of community setting (Rhoades J.A., Altman B.M., 2001). In the year 2000, about 300,000 mentally retarded and developmentally disabled beneficiaries receiving Medicaid were on HCBS Waiver (total number of mentally retarded or developmentally disabled Medicaid beneficiaries was 1.8 million, 450 thousand of whom were long term care beneficiaries) (Braddock D., Hemp R., Rizzolo M.C., 2004). That proportion has increased further in the early 2000s, and was 500,000 by 2007.

Mental retardation in Minnesota history

Minnesota was in the first third of states to implement the HCBS waiver for people mental retardation and related conditions – the MR/RC Waiver (now known as the DD Waiver) was implemented in 1984. To be eligible for the Waiver, a person must meet all of the following criteria: be eligible for Medical Assistance (MN's Medicaid) based on a disability diagnosis, have a diagnosis of mental retardation or a related condition, reside in an ICF/MR and continue to require an ICF/MR level of care or be determined by the screening team to be in danger of being placed in an ICF/MR if home

and community based services are not provided, require daily interventions, daily service needs and a 24-hour plan of care, make an informed choice of Waiver services, and have an assessed need for supports and services above those available through MA State plan. HCBS services may be provided in a person's own home, in his/her biological or adoptive family's home, in a relative's home, in a family foster care home or a corporate foster care home (group homes). The services available through the MR/RC Waiver in Minnesota include, but are not limited to, adult day care, assistive technology, case management, caregiver living expenses, day training and habilitation, extended personal care attendants (non-extended personal care attendant services are covered under non-Waivered state plan), in-home family support, personal support, respite care, supported living services, and transportation, and consumer-directed community supports (CDCS).

CDCS is a program available through the MR/DD Waiver (as well as several other HCBS waivers) that increases personal direction in the delivery of supports and allows the recipient and/or their guardians to have more flexibility and responsibility for choosing and directing their services and supports, including hiring and managing direct care staff. The goal of the program is to allow people to tailor services and supports in ways that are meaningful and unique to them and best meet their identified needs. The federal government first approved CDCS as a service of the Mental Retardation/Related Conditions Waiver in December of 1997. CDCS option did not become available statewide for all HCBS waiver recipients in Minnesota until April 1, 2005, but was utilized before that date, particularly for MR/RC Waiver recipients.

Until 1999, approximately 600 new MR/RC Waiver allocations were awarded annually, which was less than the annual increase in the number of people applying for

MR/RC Waiver services. In 2000, there were a total of about 21 thousand Medicaid beneficiaries with mental retardation and related conditions in Minnesota. Over 11 thousand of them were also long term care beneficiaries, with 8 thousand being on the MR/RC Waiver (Braddock D., Hemp R., Rizzolo M.C., 2004; Hemp R., Braddock D., 2003). In 2001, the Waiver was expanded to enroll an additional 5,000+ people. As of September 1, 2004, approximately 14,530 people in MN were receiving services through the MR/RC Waiver. Since then, there has been no great increase in the number of enrollees in the MR/RC Waiver (now called the DD Waiver) and it remains at around 15,000-16,000. This is due, in part, to the fact that currently, legislation does not allow new enrollments if they would add to the counties' budgets. However, counties can enroll new persons in the Waiver and add funds to their Waiver budget by decertifying a bed in an ICF/MR, as long as such actions do not increase the total county budget (Minnesota Department of Human Services, Disability Services Division, Jan 2005.). From 1990 to December of 2004, the number of people in Minnesota residing in ICF/MRs declined from 4,224 to 2,030 and continues to decline (Minnesota Department of Human Services, Disability Services Division, Jan 2005).

In Minnesota, the state is responsible only for oversight, policy, and waiver renewal, whereas the 87 individual counties are responsible for direct administration of Waiver and non-Waiver services. For a description of specific state and county responsibilities, see Appendix 2.

For individuals with mental retardation and developmental disabilities who are not at risk of being placed in an ICF/MR and who therefore do not qualify for the MR/DD waiver, there is another program available in Minnesota that is funded with state

and county dollars – Semi-Independent Living Services (SILS). The SILS program was developed for the express purpose of serving individuals with MR/DD who do not need 24-hour supervision. The primary focus of the program is to provide consumer with the necessary supports and instruction in all areas of life management necessary to maximize their independence in the communities where they resided. The services include training and assistance in managing money, preparing meals, self-administration of medication, shopping, keeping appointments, personal hygiene and appearance and other activities that will enable adults with MR/DD to achieve personally desired outcomes and lead self-directed lives. The ultimate goal of the SILS Program is to gradually decrease the amount of support each consumer needs until they reach the point where they are living as independently as possible.

Table 1 provides an overview of programs available to individuals with mental retardation/developmental disabilities in Minnesota discussed above.

Table 1. Programs in Minnesota

MN program	Definition
Intermediate Care Facility for Persons with Mental Retardation or Related Conditions (ICF/MR (community))	Residential facility licensed as a health care institution and certified by the Minnesota Department of Health to provide health or rehab services for persons with mental retardation or a related condition who require active treatment*. A program with Medicaid non-waiver funding.
MR/DD Waiver	Home and community-based services for children adults who are determined to

	likely require the level of care provided to individuals in an ICF/MR.
Consumer Directed Community Supports (CDCS)	Service that provides persons with a service option that increases personal direction in the delivery of supports. Families and persons participate in person centered planning, manage their direct support workers and choose their service providers*. Available through MR/DD Waiver.
Semi-Independent Living Services (SILS)	Services that include training and assistance in managing money, preparing meals, shopping, personal appearance and hygiene and other activities needed to maintain and improve an adult with mental retardation's capacity to live in the community*. Funded through the state and county, available to those who are not at risk of being placed in an ICF/MR.

* Source: Minnesota Department of Human Services, Disability Services Division. DD SD Codebook. Can be accessed at <http://www.dhs.state.mn.us>.

Definitions of mental retardation and related conditions

Mental retardation is both a condition or syndrome defined by a collection of symptoms and traits, and/or itself a symptom of other disorders such as Down syndrome or Prader-Willi syndrome (there are several hundred disorders associated with mental retardation, see American Association on Mental Retardation, 1992). As such, mental

retardation has been defined and renamed many times throughout. There are, however, consistencies across nearly all definitions – such difficulties in learning, social skills, and everyday functioning.

Some of the earlier labels placed on people with mental retardation and developmental disabilities included such terms as mental defective, imbecile, feeble-minded, moron, and idiot. They have since passed into common slang use and are no longer used in research or practice.

Swiss alchemist Paracelsus in the early 16th century (Sheerenberger, R. C., 1983) and then John Locke were the first to explicitly distinguish between mental retardation and mental illness towards the end of the 17th century. Locke wrote in his 1690 *Essay Concerning Human Understanding*: “Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few or no propositions and reason scarce at all (Doll E.A., 1962)”.

The elements of the definition of mental retardation were well accepted in the U.S. by 1900. These included: onset in childhood, significant intellectual or cognitive limitations, and an inability to adapt to the demands of everyday life. An early (1910) classification scheme proposed by the American Association on Mental Deficiency identified three levels of impairment: idiot, meaning individual whose development is arrested at the level of a 2 year old; imbecile, individual whose development is that of a 2 to 7 year old; and moron, individual whose development is equivalent to that of a 7 to 12 year old (Sheerenberger, R. C., 1983). Over the next 40 years, however, the definitions and views on mental retardation became more and more conflicting and the number of labels grew. In 1959 the American Association on Mental Deficiency (Retardation)

proposed and adopted a three-part definition that included the components of low IQ (<85), impaired adaptive behavior, and origination before age 16. In addition, a five level classification scheme was introduced to replace the previous three level system, which for obvious reasons had acquired very negative connotations: borderline (IQ 67-83), mild (IQ 50-66), moderate (IQ 33-49), severe (IQ 16-32), and profound (IQ<16). This classification was revised in 1973 to eliminate the borderline classification and change the upper IQ boundary from <84 to ≤70 and again in 1977 when the upper boundary was changed to 70-75 in cases where significant deficits in adaptive behavior were also present (Biasini F.J., Grupe L., Huffman L., et al., 2008).

In 1992 the American Association on Mental Retardation changed the definition again in favor of one with a much larger focus on the functional status, adopting the following: "Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18" (American Association on Mental Retardation, 1992). It also dropped the previous classification system. In 2002 the definition was refined further to define adaptive skill areas as consisting of conceptual skills, social skills, and practical skills. This is the definition that is most widely used in the U.S.

The DSM-IV uses the 1992 American Association on Mental Retardation definition but retains the severity level classification scheme from the 1977 definition. ICD-10 (and ICD-9) characterizes mental retardation as a condition resulting from a

failure of the mind to develop completely and distinguishes between mild (IQ 50-69), moderate (IQ 35-49), severe (20-34), and profound (IQ<20). Unlike DSM-IV and the Classification Manual of the American Association on Mental Retardation, it suggests that cognitive, language, motor, social, and other adaptive behavior skills should all be used to determine the level of intellectual impairment.

Recently, because of the social stigma attached to the term “mental retardation”, many health care practitioners and researchers began to replace it with the term “intellectual disability”.

Developmental disability is a concept related to, but not exactly the same as mental retardation. According to the Developmental Disabilities Act of 2000 (P. L. 106-402), the term developmental disability means a severe, chronic disability that 1) is attributable to a mental or physical impairment or a combination of those impairments; 2) occurs before the individual reaches age 22; 3) is likely to continue indefinitely; 4) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and 5) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. The major differences between the developmental disability definition and the American Association on Mental Retardation definition of mental retardation are in the age of onset, the fact that the developmental disability definition does not refer to an IQ requirement, and the severity of limitations. It is estimated that at least half of

individuals with mental retardation will not meet the functional limitation requirement in the DD definition (Larson S.A., Lakin K.C., Anderson L., et al., 2001).

The Medicaid Program uses the term “related conditions” in addition to mental retardation. The term is operationally very close to the definition of developmental disabilities. In 1986 the definition of “related conditions” in Medicaid regulations concerning intermediate care facilities for the mentally retarded (ICF/MRs) was amended to the following: “persons who have a severe, chronic disability that meets all of the following: 1) the disability is attributable to a) cerebral palsy, epilepsy, or b) any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons, 2) it is manifested before the person reaches age 22, 3) it is likely to continue indefinitely, 4) it results in substantial functional limitations in three or more of the following areas of major life activity: a) self-care, b) understanding and use of language, c) learning, d) mobility, e) self-direction, f) capacity of independent living” (HCFA, May 28 1986). After identifying enrollees as having either mental retardation or a related condition for eligibility purposes, the Medicaid program does not differentiate between those with mental retardation and those with related conditions in either its’ regulations and provisions or its’ documentation and data collection.

Table 2 summarizes the definitions discussed above.

Table 2. Definitions of Mental Retardation, Related Conditions, and Developmental Disabilities

Term	Definition	Diagnosis determination
Mental Retardation/ (Intellectual Disability)	American Association on Mental Retardation: the co-occurrence of significantly sub-average intellectual functioning (below 70 to 75) as measured through standardized general aptitude evaluation tools, such as the Wechsler Intelligence Scales or Stanford-Binet Intelligence Scales (mild, 50 to 69; moderate, 35 to 49; severe, 20 to 34; profound, less than 20) with related limitations in one or more adaptive skill areas: conceptual skills, social skills, and practical skills as determined by a structured evaluation tool such as the Vineland Adaptive Behavior Scales, with such limitations manifested before age 18”	Determined through established professional protocols and evaluation tools for determining that an individual has a significantly sub-average IQ and concomitant limitations in social and behavioral skills.
Related Conditions	Medicaid: persons who have a severe, chronic disability that meets all of the following: 1) the disability is attributable to a) cerebral palsy, epilepsy, or b) any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services	Defined by the presence of functional limitations in three or more areas of major life activity, but the definition lacks the standardized practices and instruments associated with the determination of mental retardation.

	<p>similar to those required for these persons, 2) it is manifested before the person reaches age 22, 3) it is likely to continue indefinitely, 4) it results in substantial functional limitations in three or more of the following areas of major life activity: a) self-care, b) understanding and use of language, c) learning, d) mobility, e) self-direction, f) capacity of independent living”</p>	
Developmental Disability	<p>Developmental Disabilities Act of 2000: a severe, chronic disability that 1) is attributable to a mental or physical impairment or a combination of those impairments; 2) occurs before the individual reaches age 22; 3) is likely to continue indefinitely; 4) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and 4) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or</p>	<p>Defined by the presence of functional limitations in three or more areas of major life activity, but the definition lacks the standardized practices and instruments associated with the determination of mental retardation.</p>

	extended duration and are individually planned and coordinated. (P.L. 106-402).	
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Prevalence of mental retardation

Estimates of prevalence of mental retardation and/or development disabilities in the United States vary and are often subject of heated debate. The percentages usually given are between 1 and 3 percent. Braddock, Hemp, and Rizzolo reported in 2004 that the percentage in 2002 was 1.58%, which translated into 4.56 million of adults and children in the U.S (Braddock, Hemp, Rizzolo, 2004). Another study estimated the prevalence of mental retardation without developmental disabilities to be just under 1 million adults and children in 1994/95, prevalence of developmental disabilities without mental retardation to be just under 2 million, and prevalence of developmental disabilities with a concurrent diagnosis of mental retardation at about 1 million adults and children (Larson S.A., Lakin K.C., Anderson L., et al., 2001).

As mentioned before, mental retardation varies in severity (no matter what definition and diagnostic criteria are used). If the bell-curve based IQ system is used, approximately 85% of people with mental retardation fall in the mildly retarded category. According to DSM-IV, persons with mild mental retardation have IQ scores from 50 to 70 or 75. They often acquire academic skills up to the 6th grade level and can become fairly self-sufficient and in some cases live independently, with some community and social support. About 10% of people with mental retardation are considered moderately mentally retarded. Their IQ scores range from 35-50, they carry out work and self-care tasks with moderate supervision, and they typically acquire communication skills and are

able to live within the community in a more supervised environment. 3-4% are diagnosed as having severe mental retardation, with IQ scores of 20-40. They may master only very basic self-care skills and some communication skills, but may still be able to successfully live in community with supervision. Only 1-2% of the mentally retarded population is considered profoundly retarded. These individuals have IQ scores under 20-25 and usually need a higher level of supervision, but may still be able to develop basic self-care and communication skills with appropriate support and training.

Importance of preventive health care for individuals with mental retardation and developmental disabilities

Life expectancy for people with mental retardation/developmental disabilities (MR/DD) has grown dramatically in recent decades. Janicki et al. examined records of 2,752 adults age 40 or older who died between 1984 and 1993 in New York State. They found that causes of death mirrored that of the general population. They also found that the mean age at death for persons with MR was 66.1 years between 1984 and 1993 (55.8 for adults with Down Syndrome), up from 59 years in the 1970s, and close to the mean age at death for the general population in 1993 of 70 years (Janicki et al., 1999).

Generally, the more severe the cognitive disability an individual has, the shorter the life expectancy (mainly due to comorbid physical problems). Overall, however, it has been projected that individuals with MR, particularly those without the most severe impairments, now have a life expectancy approximately equal to that of the general population (Janicki M.P., 1996). According to American Association on Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation), the

life expectancy of the majority of persons with mental retardation/intellectual disabilities does in fact approach or even equal that of the general population (American Association on Intellectual and Developmental Disabilities). Current estimates for adults age 60 and over with mental retardation and developmental disabilities range between 600,000 and 1.6 million and continues to grow rapidly (American Association on Intellectual and Developmental Disabilities). In 2005 in Ramsey County, Minnesota, for example, one in five MR/DD consumers served were 50 years of age or older and another 15% were between 40 and 49 years of age (Ramsey County Human Services, Developmental Disabilities Section, Dec 2006). Although these numbers under-represent children, who are mostly served through the school system instead of the county systems, they are still indicative.

The longer life expectancy means that this population now faces many of the same health risks as the general population (e.g. Ramsey County Human Services, Dec 2006). With few exceptions, the overall prevalence of common chronic health conditions such as cardiovascular disease, hypertension, cancer, lung conditions, and diabetes in persons with mental retardation and/or developmental disabilities is similar to (or even higher than) the prevalence in the general population (Hayden M.F., DePaepe P.A., 1991; Hayden M.F., Kim S.H., 2002; Traci M.A., Seekins T., Szalda-Petree A., et al., 2002; Kapell D., Nightingale B., Rodriguez A., et al., 1998). The rates for older age-related health conditions, including coronary heart disease, type 2 diabetes, some forms of cancer, osteoarthritis, disorders of hearing and vision, and dementia, are likewise similar for most people with mental retardation as compared to the general population (American Association on Intellectual and Developmental Disabilities). In addition, some

conditions are more prevalent for individuals with particular types of MR/DD, and people with MR/DD are more likely to develop certain secondary conditions in general. For example, almost 100% of people with Down syndrome over 40 years old develop early Alzheimer's disease, up to 75% develop hearing problems and/or ocular problems, up to 50% with have congenital heart disease, 15% develop hypothyroidism and 5-10% seizure disorders (Voelker R., 2002; Martin B.A., 1997). They are also about 20 times more likely to develop leukemia in childhood and 10 times more likely to develop leukemia in adulthood (Martin B.A., 1997). One study found that all individuals with MR had a significantly higher than expected age and gender-adjusted frequency of thyroid conditions, nonischemic heart disease, and visual impairment; the authors noted that this increased prevalence underscores the importance of screening and treatment for adults with MR/DD (Kapell D., Nightingale B., Rodriguez A., et al., 1998).

Research has also shown that persons with MR/DD population tend to be in poorer health. For example, Havercamp, Scandlin, and Roth (Havercamp S.M., Scandlin D., Roth M., 2004) found that adults with disabilities and, particularly, developmental disabilities, were significantly more likely to report being in fair or poor health than adults without disabilities (18.4% for DD group vs. 5.9% for no disability group). The similar or higher prevalence of chronic conditions coupled with the reported worse health in the MR/DD population means that preventive care for this population is at least as important as it is for the general population. In fact, certain preventive and screening procedures may be more recommended for MR/DD population than for the general population. Although co-morbid chronic conditions in individuals with MR/DD can no more be eliminated than they can be for the average person, it is hoped that prevention

and health promotion can reduce morbidity and mortality for this high-risk population (Marks B.A., Heller T., 2003).

It is important to note that good data on the effectiveness of preventive care in relation to improving health outcomes is surprisingly inadequate even for the general population. Most of the preventive care recommendations are based on expert-derived “knowledge” and opinion, not evidence-based research. Recently, one fascinating study by Rasmussen, Thomsen, Kilsmark, et al (2007) found that preventive health screening and consultation in primary care in 30- to 49-year-olds produce significantly better life expectancy without extra direct and total costs over a six-year follow-up period. There are also studies starting to emerge that provide evidence for specific prevention guidelines and their effectiveness in reducing morbidity and/or mortality (e.g. Snyder, Collins, 2009). Nevertheless, the possibility remains that at least some of the preventive health care services widely recommended for the general population maybe unnecessary and may in fact constitute a waste of resources. This possibility is even stronger for the developmentally disabled population because there are currently no good studies showing how effective preventive care is for them.

Disparities in preventive health care for individuals with MR/DD

There is a considerable amount of research on health and health care disparities between MR/DD and the general population, as well as between MR/DD population and individuals with other types of disabilities. Generally consistent results of that research indicate that people with MR/DD receive much less preventive health care than the general population and often less than those with other disabilities. For example, using

the North Carolina Behavior Risk Factor Surveillance System and the North Carolina National Core Indicators surveys, Havercamp, Scandlin, and Roth (2004) found significant disparities for breast and cervical cancer screening as well as for oral health care. 11.5% of women with DD have never had a Pap test as compared with 2.2% of women in no disability group; 26.8% of women with DD over 40 years of age have never had a mammogram, as compared with 13.0% of women with no disabilities; and 14.4% of people with DD either never had teeth cleaning or had no teeth cleaning for over 5 years as compared with 8.0% of people with no disabilities. Kerr, Richards, & Glover (Kerr M., Richards D., & Glover G., 1996) found that people with MR are less likely to receive preventive medical procedures, such as immunizations and cervical exams. The Special Olympics Program has screening large numbers of athletes with intellectual disabilities for vision problems and found 40% to have ocular abnormalities, with almost 20% reporting never having had an eye examination (Woodhouse et al., 2004). Studies have identified numerous unmanaged and/or undetected health conditions in people with MR, ranging from hypertension and heart disease, to fractures, to hearing and vision impairments (Howells G., 1986; Wilson D.N., & Haire A., 1990; Krahn, Hammond, Turner, 2006). The Shriver Center for Developmental Disabilities at the University of Massachusetts Medical School compiled a list of conditions that tend to go undetected in people with MR/DD. The list includes such items as gastrointestinal problems (dysphagia, esophagitis, bowel impaction, constipation), respiratory tract disease (chronic obstructive pulmonary diseases), neurological conditions (compressive neuropathies, seizure disorders), sensory impairments, oral disease, chronic or recurrent infections, and musculoskeletal conditions (osteoporosis, degenerative joint disease) (Voelker R., 2002).

Individuals with MR/DD face more barriers accessing health care than the general population (Kastner T., Walsh K., Criscione T., 1994; Lennox N.G., Kerr M.P., 1997). Several important contributing factors have been identified. One is that many physicians are unprepared or unwilling to provide preventive care to people with MR/DD (Hayden M.F., Kim S.H., 2002; Lennox N.G., Kerr M.P., 1997; Waldman H.B., Perlman S.P., 2002). They have not had the training or the experience to provide health care services for adults with MR/DD and are often reported as not having the knowledge and sensitivities about the disability, not being able to separate the disability diagnosis from the person, and not being able to focus on other health problems (Marks B.A., Heller T., 2003). The second factor is well documented - many physicians don't want to treat people covered by Medicaid because of low reimbursement rates (e.g., Reichard A., Turnbull III H.R., 2004). Thirdly, there may be a societal value judgment, by which consciously or subconsciously people with mental retardation are not considered to be as "worthy" of receiving health care services as people without, especially in a limited resource health care system. The difference in health status and/or health care access is particularly evident for people with more severe disabilities (Krahn, Hammond, Turner, 2006).

Residential arrangements and preventive health care

The de-institutionalization movement of the developmentally disabled population was a welcome change to most recipients and their families. Living in community-based residences often improves outcomes such as consumer choice, contacts with family and community integration, as well as service costs (Stancliffe, Lakin, 1998). However, one of the advantages of institutions such as large ICF/MRs is the centralization of health care and oversight, even as it comes at the expense of personal choice. Institutions usually have a medical professional on their staff and preventive medical services such as vaccines, physical exams, dental and vision exams are often performed on site. Community-based residential options, on the other hand, do not have nearly the level of health care centralization and oversight that, for example, large ICF/MRs do. Health services for individuals with MR/DD have not advanced at the same rate as de-institutionalization services and the increased autonomy associated with de-institutionalization may lead to undesirable health outcomes among this population (Shavelle and Strauss, 1999).

Because most people with MR/DD receive (or need) some help navigating the health care system to ensure timely and appropriate receipt of preventive health care, the role of supporting persons and residential arrangement becomes very important. Residential providers and/or other supporting persons such as family members are responsible for recognizing the necessity of a health care service/procedure. It has been documented, however, that providers often do not recognize the problems or warning signs (Krahn, Hammond, Turner, 2006). Providers and supporting persons are also usually responsible for making and keeping health care appointments for the individual

with MR/DD, as well as for finding a doctor who is capable (trained and experienced) and willing to treat persons with MR/DD. Furthermore, they are often the primary advocates for individuals with MR/DD at the point of contact with medical care providers and often have to communicate necessary information to the physicians.

It has been documented that the characteristics of the residential environment the individual is living in can affect his/her receipt of preventive medical care. The health and health care of persons with MR/DD varies by residential arrangement. Individuals with MR/DD living in a family home, for example, may be in somewhat poorer health than individuals living in other types of arrangement, such as group homes or institutions (e.g. Rimmer J.H., Braddock D., Marks B. (1995) found that people in institutions had lower body weights and BMIs, as well as lower total cholesterol and LDL-C levels) and may be less likely to receive preventive medical care (e.g., to have received a physical exam in the past year, to have had a dental visit within the last six months, to have received an ob/gyn exam in the past year, to have received a flu vaccine, TB test, etc.). Freedman and Chassler (2004), for example, found that only 90.7% percent of adults with MR/DD in their study who lived in a parent's or a relative's home received a physical exam in the past year, as compared to 96.8% of those living in a community residence and 100% of those living in an institutional facility. 72.4% of those living in a parent's/relative's home received a dental exam within the past 6 months as compared to 82.1% of those in a community residence and 87.9% of those in institutions. 27.2% of adult females living in a parent's/relative's home have never had an ob/gyn exam as compared to only 8.4% of those in a community residence and 2.6% of those in an institutional facility. A California study found that people with intellectual disabilities

living in community-based group homes were more likely to have a personal dentist or physician, more likely to have a normal body mass index, and less likely to be obese than people living in the community with family or friends or on their own (Lewis et al., 2002).

With the increased importance of the HCBS Waiver for the MR/DD population, more and more individuals with MR/DD have been living in community-based small group homes and foster care homes. However, other residential arrangements are also common. The most common of these is a family home – more so for children with MR/DD than for adults. A significant percentage of adults with MR/DD live in their own homes with varying level of supervision and support, and a small percentage live in nursing homes (usually the aged with considerable daily medical needs).

Intermediate Care Facilities for the Mentally Retarded also have still have a large presence, particularly for older individuals. In Minnesota, remaining ICF/MRs vary both in location and structure and size, serving anywhere from four to sixty four people. Apart from more oversight and perhaps higher staff-to-consumer ratios, smaller ICF/MRs differ little structurally from a HCBS Waiver-paid community-based group homes, and rely on medical services located in the community. Minnesota's large ICF/MRs, however, retain many of the features of old-style institutions, including centralization and presence of medical staff.

Despite advanced recognition that preventive health care is important for this population and evidence that place of residence affects that care, there exist large inadequacies in the quality and quantity of available information. Studies investigating the differences in disabilities level and receipt of preventive health care between different

residential arrangements for individuals with MR/DD have largely been descriptive, small-scale and limited in scope. Furthermore, the results are often generalized to people with all levels of disability (Frey, Temple, Stanish, 2006). Prior studies have found it difficult to control for the potential differences in the level of disability between individuals in different residential arrangements when differences in receipt of preventive health care were of interest. This research will address both of these concerns – it will utilize large administrative data sets to capture the whole of MR/DD population receiving Medicaid services in Minnesota because of their MR/DD diagnosis and it will directly control for differences in several types of disability between persons living in different residential circumstances.

IV. Specific aims

The present research aims to answer two broad questions – does where the person live affect his/her likelihood of receiving recommended preventive health care and does the person’s insurance status (namely, being dually-eligible) affect that likelihood?

Research question 1: How do level of different types of disabilities and receipt of preventive care vary across different residential arrangements for MR/DD adults receiving services in Minnesota? Of secondary interest are CDCS and SILS programs. An attempt will be made to investigate how disability differs for the participants of CDCS and SILS programs as opposed to non-participants.

We propose that there are differences in the likelihood of MR/DD adults receiving preventive medical care across different residential arrangements and programs. Residents’ levels of disability are also likely to vary across these residential arrangements and programs. Hypotheses 1-5 are basically descriptive and aim to explore the differences in disability level between residences and programs. Hypotheses 6-9 examine the differences in preventive health care utilization. At least some of the differences in receipt of preventive care across residential arrangements should be explained by the differences in disability levels (Hypotheses 6-7). However, even controlling for these characteristics, differences are likely to remain in the likelihood of MR/DD adults receiving preventive medical care across residential arrangements and programs (Hypotheses 8-9).

Hypothesis 1: Those MR/DD adults living in their own homes have a less severe level of cognitive and physical disabilities, fewer functional limitations and behavioral issues and higher communication ability than those in all other residential settings.

Rationale: Prior existing research has demonstrated this correlation. Also preliminary data exploration shows that those in own homes generally have higher mobility, higher level of receptive, more self-care skills, more daily living/house management skills, lower level of behavioral problems as demonstrated by physical aggressiveness and self-injurious behavior, and higher level of expressive communication.

Hypothesis 2: Those living in family homes are younger and have fewer behavioral issues than those in foster/group homes and ICF/MRs.

Rationale: Prior research has documented this correlation. Preliminary data exploration shows that those living in family homes are younger, and have a lower level of behavioral problems as demonstrated by physical aggressiveness and self-injurious behavior than those in foster with staff homes and ICF/MRs.

Hypothesis 3: Those living in ICF/MRs are more disabled, both physically and cognitively, and have more behavioral issues than those in all other residential settings.

Rationale: Prior research has documented this correlation. In addition, preliminary data exploration shows that those in ICF/MRs have lower mobility, lower level of receptive communication, fewer self-care skills, fewer daily living/house management skills, and a higher level of behavioral problems as demonstrated by physical aggressiveness and self-injurious behavior.

Hypothesis 4: Those MR/DD adults in SILS program have a less severe level of cognitive and physical disabilities, fewer functional limitations, fewer behavioral issues and higher

communication ability than those who are in the CDCS program or who are not in either program.

Rationale: SILS is a program for those MR/DD adults who do not need an ICF/MR level of care and thus do not qualify for the MR/DD waiver. Not needing ICF/MR level of care should mean a lower level of disability and fewer limitations. Preliminary data exploration shows that those in SILS program have higher mobility, higher level of receptive communication (as proxy for the level of cognitive disability), more self-care skills, more daily living/house management skills, lower level of behavioral problems as demonstrated by physical aggressiveness and self-injurious behavior, and higher level of expressive communication.

Hypothesis 5: Those living in foster/group homes who are in the CDCS program are younger, less cognitively and physically disabled, with fewer behavioral issues and functional limitations and with higher communication ability than those living in foster/group homes who are not in CDCS (or SILS) program.

Rationale: CDCS is a waiver program that gives people with MR/DD and their family or guardians more flexibility and responsibility for directing their services and supports, including hiring and managing direct care staff. Although the CDCS program is supposed to not prevent entrance into the program based on disability level, it is likely that those with higher communication ability are better able to express their desire to utilize it. Furthermore, it is possible that family/guardians of more physically and cognitively disabled adults do not think that their dependent adults have as much to gain from the program; it is also possible that there is a bias in the system against enrolling more disabled adults. Because a large proportion of recipients who were newly enrolled

in the MR/DD Waiver in 2001 were enrolled through the CDCS option, CDCS participants will tend to be younger. Preliminary data exploration shows that people living in foster homes with staff who are in the CDCS program have higher mobility, higher level of receptive communication, more self-care skills, more daily living/house management skills, lower level of behavioral problems as demonstrated by physical aggressiveness and self-injurious behavior, and higher level of expressive communication than those living in foster homes with staff who receive waiver services but are not in the CDCS program.

Hypothesis 6: The more physically and cognitively disabled MR/DD adults are less likely to receive preventive care.

Rationale: Prior research has documented that individuals with MR/DD face more barriers accessing health care than the general population. Some of the contributing factors may be unwillingness of physicians to treat MR/DD patients and a societal bias that people with MR/DD may somehow not be as “worthy” of receiving medical care. It is logical to extend that observation and theorize that the more disabled an individual with MR/DD is, the more barriers exist for him/her.

Hypothesis 7: MR/DD adults with more communication skills/ability are more likely to receive preventive care.

Rationale: More communication ability may allow MR/DD adults to better advocate for themselves with regard to their medical care with both staff and physicians.

Hypothesis 8: Controlling for disabilities, MR/DD adults living in own or family homes are least likely to receive recommended preventive medical care, whereas MR/DD adults

living in ICF/MRs are most likely to receive preventive care, with foster/group homes falling somewhere in the middle.

Rationale: Considerable amount of research has shown that the correlation between residential setting and receipt of preventive medical care exists, although other factors have not usually been well controlled for and existing research has mostly utilized small samples. ICF/MRs usually have the most structured environment with the closest supervision, and sometimes nurses or doctors available on-site do perform simple procedures such as involved in preventive care. Family or own homes have the least amount of supervision with few immediate available reminders or incentives to adhere to recommended preventive care.

Hypothesis 9: Controlling for other factors, MR/DD adults in CDCS are more likely to receive recommended preventive medical than those not in either SILS or CDCS program.

Rationale: The goal of the CDCS program is to improve the quality of community care through increased consumer control without increasing its' costs. It is supposed to allow consumers or their guardians to hire and train their own staff (including training family members), such as personal assistance, purchase certain environmental modifications and provisions. If MR/DD adults and/or their caretakers/guardians are better able to control their environment, it is likely that they will hire and train staff and provide necessary supports to also be able to receive necessary health care, including recommended preventive services.

Research question 2: How does receipt of preventive care vary across MR/DD adults with dual coverage (Medicare and Medicaid) and Medicaid-only coverage?

We propose that MR/DD adults with dual coverage differ in the likelihood of receiving preventive medical care from MR/DD adults with Medicaid-only coverage. Some of the difference in the likelihood of receiving preventive care can be explained by differences in disabilities. However, even controlling for these factors, those with dual coverage differ in the likelihood of receiving preventive medical care from those without dual coverage.

Hypothesis 10: Controlling for disability and place of residence, MR/DD adults with dual coverage are more likely to receive preventive care than those with Medicaid-only coverage.

Rationale: Medicaid's low reimbursement rates for medical procedures and physicians' services may make it difficult for MR/DD adults to access recommended preventive services due to unwillingness of many physicians to treat Medicaid. Furthermore, it is possible for MR/DD adults to lose their Medicaid coverage for a month or more if the assets exceed a certain limit (\$2,000). If, in addition to Medicaid, the person is covered by Medicare, Medicare becomes the primary insurance for health care services.

Medicare's reimbursement rates for medical procedures are higher than Medicaid's and even if the person becomes ineligible for Medicaid for a period of time, he/she maintains their Medicare eligibility. An MR/DD adult who is eligible for both Medicare and Medicaid, therefore, should be more likely to receive preventive care due continuity of health insurance coverage, and higher reimbursement rates.

V. Methods and Preparation

Data sources

Three large administrative databases were utilized for the analysis. Medicaid and Medicare payment data for years 2001-2002 were used to measure utilization of preventive health care services. The state of Minnesota's MMIS (Medicaid Management Information System) database containing DD screening documents (form DHS-3067) for years 2001-2002 was used to create measures for the level of disability as well as place of residence for all persons receiving state plan or waiver services. The DD screening document is completed out by screening teams to determine the level of care required for a person with a diagnosis of mental retardation or a related condition. This can occur when a person is judged to be at risk of placement in an ICF/MR or a nursing facility, or is requesting services in the areas of residential, training and habilitation, nursing facility or family support. There are also mandatory periodic (e.g. annual) screenings, as well as screenings for circumstances when service needs of the persons have changed or are anticipated to will have changed in the near future. The DD screening document contains information on the person's diagnoses, functional strengths and needs, and current and planned services and residential arrangements. There were 15,352 persons with DD screening documents in 2001-2002 at least 18 years of age at the time of the assessment. The total number of valid DD screening documents in years 2001-2002 for these recipients was 37,504. The number of assessments per recipient in the two-year period varied from 1 to 12, with a median of 2. The overwhelming majority of recipients had either 2 (37.4%) or 3 (30.4%) assessments.

Software

All analyses were performed using SPSS v.17.

Defining residences and programs of interest

There are four major residential arrangements in which adults with mental retardation and developmental disabilities in Minnesota can be found and which are of interest for this analysis. The general types of residential arrangements that will be investigated are: foster/group home, family home, own home, and Intermediate Care Facility for people with MR (ICF/MR). As discussed in the introduction, ICF/MR, in addition to being a place of residence, is also a Medicaid program with its own funding different from the MR/DD Medicaid waiver. As also mentioned in the introduction, there are both large and small ICF/MRs in existence in Minnesota. Small ICF/MRs may have as few as four residents and, other than the amount of oversight and staffing, are not very different from community-based foster/group homes. Larger ICF/MR are more centralized and retain many of the features of old-style institutions. The Minnesota DD screening document specifies only the source of funding and not the size of the residence, so we will not be able to distinguish between smaller and larger ICF/MRs. This will likely have the effect of biasing any difference we find between ICF/MRs and foster/group homes down.

In addition, we will attempt to look at a program that is available to HCBS Waiver enrollees - Consumer-Directed Community Supports (CDCS) and a program that is available to recipients who do not qualify for the HCBS Waiver - and Semi-Independent Living Services (SILS). Both CDCS and SILS programs are available to

people regardless of their place of residence (with the exception of residents of ICF/MRs). Recipients can also receive waiver services and not be in the CDCS program (or SILS program).

DD screening documents from the MMIS provide information on the recipient’s place of residence, as well as whether the recipient was enrolled in one of the programs of interest. Residence classifications and their definitions found in the state assessments, as well as the general residence type to which they will be assigned for the purposes of future analysis are given in table 3 below.

Table 3. Residence grouping

DD screening document residence	DD screening document definition *	Residence grouping
Home of immediate family	Person lives with parents, siblings or spouse.	Family home
Home of extended family	Person lives with a relative who is not a parent, sibling or spouse.	Family home
Foster care (family)	Person lives with a person or family unit licenses under the Department of Human Services’ child or adult foster care rules who functions as a “primary caregiver”, that is someone who is principally responsible for the care and supervision of the person and maintains their primary	Family home

	residence at the same address as the person and is named as the owner or lessor of the primary residence.	
Foster care (live-in caregiver)	Person lives in a licensed foster home where the primary caregiver responsible for the care and supervision of the person is employed to provide the service, maintains their primary residence at the same address as the person, but does not own or lease the residence.	Foster/group home
Foster care (shift staff)	Person lives in a licensed foster home where the care and supervision of the person is provided by two or more employed persons who do not maintain their primary residence at the same address as the person and who have no investment in the ownership of the residence.	Foster/group home
Own home (unlicensed with less than 24-hour supervision)	Person lives in a home that is not licensed under any Department of Human	Own home

	Services or Department of Health rules and receives supervision and perhaps support services for less than 24 hours per day. May have a 24-hour plan of care.	
Own home (unlicensed with 24-hour supervision)	Person lives in a home that is not licensed under any Department of Human Services or Department of Health rules and receives 24-hour supervision and perhaps support services.	Own home
ICF/MR – community	Person lives in a residential facility licensed as a health care institution and certified by the Minnesota Department of Health to provide health or rehabilitative services for persons with mental retardation or a related condition who require active treatment.	ICF/MR
Temporary care – ICF/MR (community)	Provision of services in a community ICF/MR for a time-limited period for adults or children requiring ICF/MR level of care.	ICF/MR

* Source: Minnesota Department of Human Services, Disability Services Division. DD SD Codebook. Can be accessed at <http://www.dhs.state.mn.us>.

The two programs of interest and their definitions found in the DD screening document are given in table 4.

Table 4. Programs of interest

DD screening document program	DD screening document definition *
Consumer Directed Community Supports (CDCS)	Service that provides persons with a service option that increases personal direction in the delivery of supports. Families and persons participate in person centered planning, manage their direct support workers and choose their service providers.
Semi-Independent Living Services (SILS)	Services that include training and assistance in managing money, preparing meals, shopping, personal appearance and hygiene and other activities needed to maintain and improve an adult with mental retardation's capacity to live in the community. SILS are state and county funded.

* Source: Minnesota Department of Human Services, Disability Services Division. DD SD Codebook. Can be accessed at <http://www.dhs.state.mn.us>.

Each of the 37,504 valid state assessments for adults in 2001-2002 was assigned a flag for family home, own home, foster/group home, ICF/MR, CDCS and SILS based on the definitions described above. A very small number of assessments (75) contained

conflicting residence and/or program information. We decided to treat assessments with conflicting residential and/or program information by assigning to them a residence flag and/or program flag which were more staff-intensive. This decision is admittedly somewhat arbitrary. The rationale behind this treatment of conflicting information was that if a person is coded on the same assessment as living, for example, both in the home of immediate family and in foster care with shift staff, then it is not illogical to think that the person either was living recently or is expected to live shortly in foster care with shift staff at least temporarily. The other option was to simply drop the assessments with conflicting residence and/or program. Because of the very small number of affected assessments, the decision not to drop them does not affect the results. Table 5 presents frequencies and cross-frequencies of places of residence and programs. The totals are the number of assessments, not the number of residents.

Table 5. Places of residences and programs associated with all DD screening documents

	Program			Total
	<i>CDCS</i>	<i>SILS</i>	<i>Neither</i>	
Place of residence				
<i>Family home</i>	1,716	260	7,947	9,923
<i>Foster/group home</i>	574	43	16,996	17,613
<i>Own home</i>	203	913	1,768	2,884
<i>ICF/MR</i>	0	0	5,245	5,245
<i>Other/Unknown</i>	24	117	1,698	1839
Total	2,517	1,333	33,654	37,504

The vast majority of assessments where residence was classified as other/unknown had either nursing facility specified as the source of funding (56%), or “other” specified for place of residence (26%). Where “other” is specified, the assessment directs the person filling it out to specify the place of residence in notes, but that data is not available. This other/unknown category is not of major interest in further analysis, but as we show subsequently, persons in other/unknown residential arrangements are approximately similar in their disability levels to persons living in ICF/MRs. The vast majority of assessments filled out in 2001-2002 specified neither CDCS nor SILS programs. As was mentioned in the introduction, Consumer Directed Community Supports (CDCS) is a program that did not start being widely utilized in Minnesota until 2005. Since the data here is from years 2001-2002, relatively few people are seen participating in CDCS, as expected.

People can either remain in the same residence and/or program during the two years of available data or they can switch either place of residence, or program, or both. The majority of recipients were in the same residence/program combination during the entire follow-up period. Table 6 contains the frequencies and cross-frequencies of places of residences and programs for recipients for whom residence type and program did not change during the two-year span (or for whom only one assessment is available during the two years (2,277 consumers)). Table 7 presents the frequencies at the beginning and at the end of the follow-up period for consumers who shifted between residences and programs during the two years. The totals in both tables are the number of residents. As is evident from table 7, consumers most often switched from living in a family home or

an ICF/MR to living in a foster/group home and from not being enrolled in CDCS program (or SILS) to becoming enrolled in CDCS.

Table 6. Places of residences and programs for people who remained in same type of residence and program

	Program			Total
	<i>CDCS</i>	<i>SILS</i>	<i>Neither</i>	
Place of residence				
<i>Family home</i>	497	67	2,753	3,317
<i>Foster/group home</i>	153	6	5,791	5,950
<i>Own home</i>	40	311	534	885
<i>ICF/MR</i>	0	0	2,184	2,184
<i>Other/Unknown</i>	6	39	488	533
Total	696	423	11,750	12,869

Table 7. Frequencies of shifting between residences and programs

	At end of follow-up period													
	<i>Family home/CDCS</i>	<i>Family home/SILS</i>	<i>Family home/Neither</i>	<i>Foster home/CDCS</i>	<i>Foster home/SILS</i>	<i>Foster home/Neither</i>	<i>Own home/CDCS</i>	<i>Own home/SILS</i>	<i>Own home/Neither</i>	<i>ICF/MR</i>	<i>Other/CDCS</i>	<i>Other/SILS</i>	<i>Other/Neither</i>	Total
At beginning of follow up														
<i>Family home/CDCS</i>	1	1	9	19	0	15	2	0	0	1	0	0	1	49
<i>Family home/SILS</i>	13	1	79	4	1	17	2	2	8	0	0	0	0	127
<i>Family home/Neither</i>	459	11	29	33	1	351	8	5	40	30	0	0	51	1,018
<i>Foster home/CDCS</i>	4	0	0	2	0	12	0	0	0	1	0	0	1	20
<i>Foster home/SILS</i>	0	0	4	0	0	22	0	0	0	0	0	0	1	27
<i>Foster home/Neither</i>	11	0	45	85	0	53	3	2	14	19	0	0	84	316
<i>Own home/CDCS</i>	0	0	1	0	0	1	0	0	1	0	0	0	1	4
<i>Own home/SILS</i>	3	2	14	2	0	28	32	4	144	1	2	0	11	243
<i>Own home/Neither</i>	2	0	17	2	1	41	29	25	9	2	0	2	21	151
<i>ICF/MR</i>	2	0	6	18	0	249	1	0	0	13	0	0	29	318
<i>Other/CDCS</i>	1	0	0	0	0	1	0	0	0	0	0	0	0	2
<i>Other/SILS</i>	0	0	2	0	0	5	2	3	10	0	2	0	9	33
<i>Other/Neither</i>	6	0	26	6	0	80	5	4	14	20	1	1	12	175
Total	502	15	232	171	3	875	84	45	240	87	5	3	221	2,483

Our major question of interest is whether the recipient's place of residence affects his/her receipt of preventive health care. It is therefore important for those who change type of residence and/or program during the two-year period whether their place of residence is assigned at the end of follow-up period or the beginning. We decided to use person's latest assessment to assign their residence. Implications of this decision are discussed in the limitations section.

Creating Measurement Instruments for Physical, Functional, Behavioral, Communication, and Cognitive Disabilities

In order to approach our hypotheses of interest, it is necessary to operationalize disability. A priori, several kinds of disability are of interest to us: physical (describing the level of bodily disability), cognitive (describing the level of mental cognition disability), behavioral (describing the level of inappropriate/antisocial/harmful behaviors), communication (describing the level at which the person is able to communicate with others) and functional (describing the extent to which the person is limited in performing everyday tasks, partially by the other four disabilities).

There are some scales and instruments that have been created or adapted from other instruments by others to measure these types of disabilities in the general population and that are commonly used in research. For example, Katz Activities of Daily Living scale (consisting of bathing, dressing, toileting, transferring, continence, and feeding items) and Lawton Instrumental Activities of Daily Living scale (consisting of items regarding the ability to use a telephone, shopping, food preparation, housekeeping, laundry, transportation, medications responsibility, and finances) were

developed and are used to measure the functional status of a person and to evaluate the type and amount of health care services the person may need ("Activities of Daily Living Evaluation." Encyclopedia of Nursing & Allied Health. Ed. Kristine Krapp. Gale Group, Inc., 2002. eNotes.com. 2006. [Enotes Nursing Encyclopedia](#)). Cognitive Performance Scale (CPS) was created in 1994 by adapting items from the Minimum Data Set (MDS) used in nursing facilities and is used to measure cognitive disability and assign residents into cognitive performance categories (Morris, Fries, Mehr, et al. "MDS Cognitive Performance Scale". J Gerontol. 1994 Jul; 49(4): M174-82.). However, even though instruments for measuring disability like the ones described above are well known and well documented, they are of no use in our present research. The items necessary to create these scales are not found in either the DD screening document, or in the Medicaid and Medicare utilization files. We thus have to create our own measures of disability levels.

The state assessment (i.e., DD screening document), which will be used to create disability scales, is a service-oriented document. It was designed to measure the overall disability and associated need for waiver or other kinds of services for the MR/DD population. It does not include items for measuring ADLs or cognition or any other conventional disability scales, nor is it good at explicitly distinguishing between various types of disability. For this reason, we will use the items available in the document and attempt to combine them to create measures of different types of disability.

Candidate items for disability measurement instruments were selected based on their content and subject matter and are as follows:

- Physical Disability:

- Vision (1. No impairment. 2. Impairment corrected to normal with glasses or contacts. 3. Difficulty at level of print, graphics, or small objects. 4. Difficulty at level of obstacles in environment. 5. No useful vision. 99. Unknown).
- Seizures (1. No history or evidence of seizures. 2. History of seizures, none recently. 3. Seizures – controlled. 4. Seizures – partially controlled. 5. Seizures – uncontrolled. 99. Unknown).
- Mobility (1. No impairment. 2. Walks short distances independently. 3. Walks aided (walker, crutches, assistance of a person, etc). 4. Propels own wheelchair – bears weight for transfers. 5. Propels own wheelchair – total assistance with transfers. 6. Uses electric wheelchair. 7. Unable to propel wheelchair. 8. Not mobile due to overriding medical condition. 99. Unknown).
- Fine Motor Skills (1. No impairment. 2. Impairment present – minimal effect on movement. 3. Impairment – requires occasional assistance. 4. Impairment – requires frequent assistance/adaptations. 5. Impairment – requires constant assistance/adaptations. 6. Overriding medical condition – participation limited. 99. Unknown).
- Functional Disability:
 - Mobility (1. No impairment. 2. Walks short distances independently. 3. Walks aided (walker, crutches, assistance of a person, etc). 4. Propels own wheelchair – bears weight for transfers. 5. Propels own wheelchair – total assistance with transfers. 6. Uses electric

wheelchair. 7. Unable to propel wheelchair. 8. Not mobile due to overriding medical condition. 99. Unknown).

- Independent Living Skills: A. Self-Care. B. Daily Living Skills/House Mgmt. C. Money Management. D. Community Living. E. Leisure & Recreation (1. Independent. 2. Minimal supervision (formal program not needed). 3. Instruction required with expected outcome of increased independence. 4. Person participates with another's assistance for all or portions of an activity. 5. Person unable to participate in activity).
- Behavioral Disability:
 - Challenging (Excess) Behavior Scales: A. Eating Non-nutritive Substances (Pica). B. Injurious to Self. C. Aggressive, Physical. D. Aggressive, Verbal/Gestural. E. Inappropriate Sexual Behavior. F. Property Destruction. G. Runs Away. H. Breaks Laws. I. Temper Outbursts. J. Other (1. None. 2. Mild. 3. Moderate. 4. Severe. 5. Very severe. 99. Unknown)
- Communication Disability:
 - Hearing (1. No impairment. 2. Loss present, no correction needed. 3. Impairment – correctable (with aid). 4. Impairment – not correctable. 5. Responds to alarm sounds or intense, low frequency noises. 6. No useful hearing/deaf. 99. Unknown).
 - Expressive communication (1. Functional. 2. Speech intelligible to familiar listeners. 3. Speech difficult to understand. 4. Speech

unintelligible even to familiar listeners. 5. Combines signs and/or gestures to communicate. 6. Uses single signs or gestures to express wants and needs. 7. Uses augmentative communication aid. 8. Does not have functional expressive communication. 99. Unknown).

- Receptive communication (1. Comprehends conversational speech. 2. Comprehends phrases with gestural cues/modeling prompts. 3. Limited comprehension – one to two words. 4. Comprehends signs/gestures/modeling prompts. 5. Does not comprehend verbal, visual, or gestural communication. 99. Unknown).

- Cognitive Disability:

- ICD-9 codes for level of mental retardation: 317 – mild mental retardation, 318.0 – moderate mental retardation, 318.1 – severe mental retardation, 318.2 – profound mental retardation.

The next step is to test whether the assessment data supports the use of the candidate items and whether they can be combined in a meaningful way to form the disability measurement instruments. Items need to be rescaled to a common scale so that items with more categories (e.g. 1 through 8) are not weighed more heavily than items with fewer categories (e.g. 1 through 5). To begin with, all items were treated as continuous because the available response categories generally follow a pattern of increasing disability. They were then rescaled to a common scale of 1 through 10 by anchoring the extreme disability and least disability response categories at 10 and 1, respectively, and spreading the remaining response categories at equal intervals. For example, the possible scores for Self-Preservation after rescaling are 1, 5.5, and 10, the

possible scores for Vision are 1, 3.25, 5.5, 7.75, and 10; the possible scores for Mobility after rescaling are 1, 2.28, 3.56, 4.84, 6.12, 7.40, 8.68, and 10, and so on. The alternatives were to 1) rescale the items to a different common scale, 2) rescale the items to different scales, or 3) not rescale the items. Rescaling the items to a different common scale would not affect the results. A scale of 1 to 10 was thought to be more easily interpretable. Rescaling the items to different scales or not rescaling them at all is in effect analogous to implicitly weighing different items differently. Weighing items differently requires some a priori assumptions about which items are better or more dominant indicators of the various kinds of disability. Since there are no a priori assumptions about the importance of individual items, a decision was made to treat all items as being equally important and contributing the same amount of information. For example, an “unable to participate” in money management was considered to be as indicative of functional disability (presumably) as a “not mobile due to overriding medical condition”.

We selected the latest assessment for each person (the same assessment that was used to assign place of residence for that person) and performed disability descriptive and factor analyses on those assessments. Factor analysis was performed with the rescaled candidate items. Factor analysis is a technique used to uncover the latent structure, or dimensions of a set of variables by analyzing correlations between them. The purpose of factor analysis is to discover simple patterns in the pattern of relationships among the variables. In particular, it seeks to discover if the observed variables can be explained largely or entirely in terms of a much smaller number of variables called *factors*. In our case, it will be used to validate the proposed a priori

disability scales by checking to see that the candidate items load on the anticipated factors (types of disability). We chose to use Principal Components extraction method because it does not have any distributional assumptions; specifically, it does not require multivariate normality of items.

We considered using the more easily interpretable varimax rotation, which results in orthogonal (uncorrelated) factors. However, since the components in this case all measure different facets of disability, it is intuitively clear that they are not completely independent of each other and thus should be allowed to correlate. We thus used promax rotation, which does not require the new axes (components) to be orthogonal to each other, allowing the factors (types of disability) to correlate.

Figures 1 and Table 8 below present the scree plot and the structure matrix for factor analysis using all candidate items. A scree plot is a graph that shows the fraction of total variance in the data as explained or represented by each component. It plots the eigenvalues of the correlation matrix of the items. A component's eigenvalue represents the proportion of total variance that component extracts. The usual rule of thumb is to retain components with eigenvalues of 1 or greater. The structure matrix contains factor loadings of each item on each extracted component. Factor loadings are the correlations between the items and the components. The higher the correlation, the more evidence that the item belongs in that component.

Figure 1. Scree plot, all candidate items, promax rotation ($\kappa=4$), principal components extraction method

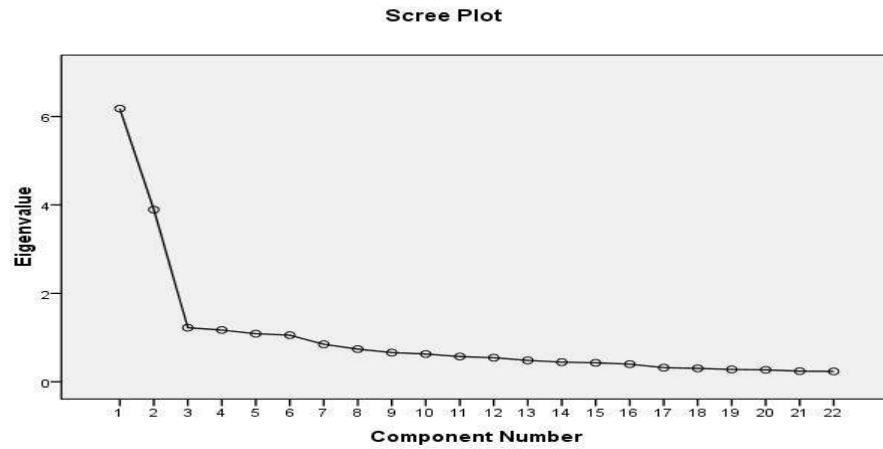


Table 8. Structure matrix, all candidate items, promax rotation ($\kappa=4$), principal components extraction method

Structure Matrix

	Component					
	1	2	3	4	5	6
mobility	.584	-.186	.796	.091	-.128	.437
express. commun.	.671	-.041	.496	.660	-.091	.440
vision	.189	-.050	.414	-.092	-.013	.636
seizures	.254	.047	.685	.207	-.057	.039
recept. commun.	.567	-.009	.465	.656	-.043	.536
self care	.832	.092	.558	.334	-.027	.319
house managem.	.840	.069	.504	.299	-.027	.294
money managem.	.791	.074	.342	.386	-.039	.260
community living	.839	.120	.327	.272	.027	.223
leisure	.831	.118	.353	.304	.028	.232
pica	.207	.200	.067	.741	.108	.001
injurious to self	.263	.601	.107	.518	.230	.077
runs away	.088	.499	-.102	.383	.567	-.124
aggress phys	.188	.861	-.010	.287	.358	-.031
aggress verb	-.021	.826	-.122	-.099	.361	-.112
property destruct	.144	.789	-.052	.376	.386	-.042
breaks law	-.111	.284	-.110	-.043	.839	-.101
temper tantrums	.104	.880	-.052	.125	.336	-.051
inapprop sex behav	.025	.389	-.125	.145	.782	-.068
fine motor skills	.638	-.071	.791	.254	-.072	.396
hearing	.112	-.020	-.048	.173	-.059	.763
self preserv	.741	.136	.420	.391	-.026	.297

Extraction Method: Principal Component Analysis.
Rotation Method: Promax with Kaiser Normalization.

The scree plot in Figure 1 indicates that two components are most important in describing the underlying variance; however, there are a total of six components with eigenvalues greater than 1. Thus six components were retained. One of these components consisted of only the Pica (eating non-edible substances) item clearly falling into it. An attempt to force a five-factor structure did not result in Pica item falling into a component with any of the other items. Pica by itself does not hold much interest for us in describing the relationship between disability, residence and receipt of preventive care. We thus decided to drop the Pica item from consideration and re-ran the factor analysis with remaining items. The new scree plot and structure matrix are presented in Figure 2 and Table 9.

Figure 2. Scree plot, dropped Pica item, promax rotation ($\kappa=4$), principal components extraction method

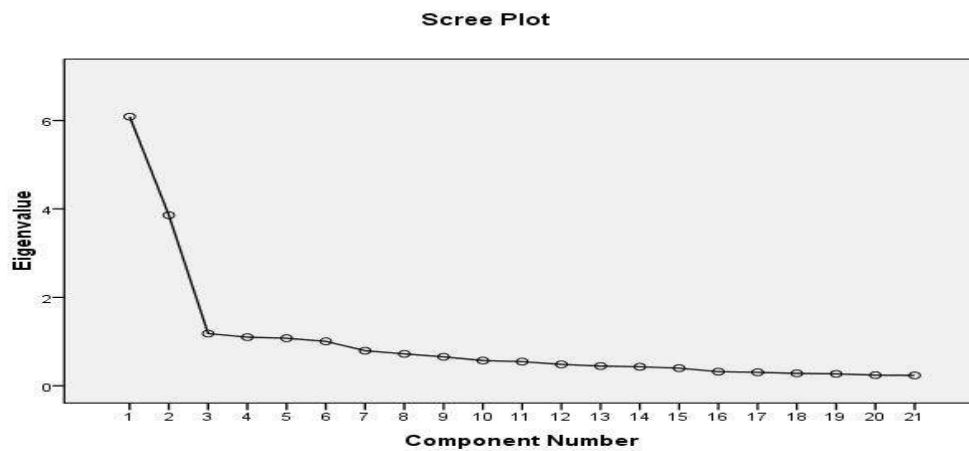


Table 9. Structure matrix, dropped Pica item, promax rotation ($kappa=4$), principal components extraction method

	Component					
	1	2	3	4	5	6
mobility	.592	-.182	.719	-.129	.290	.434
express. commun.	.644	.013	.543	-.036	.776	-.062
vision	.194	-.051	.190	-.056	.124	.812
seizures	.271	.049	.744	-.034	.184	-.007
recept. commun.	.530	.048	.487	.007	.826	.001
self care	.836	.110	.552	-.009	.402	.156
house managem.	.844	.085	.498	-.010	.367	.146
money managem.	.786	.101	.365	-.011	.441	.003
community living	.842	.135	.330	.041	.313	.075
leisure	.833	.135	.361	.045	.341	.066
injurious to self	.262	.631	.170	.261	.354	-.171
runs away	.089	.517	-.009	.593	.171	-.305
aggress. phys.	.188	.867	.041	.367	.136	-.147
aggress. verb.	-.012	.802	-.133	.334	-.207	.035
property destruct.	.144	.803	.013	.403	.184	-.203
breaks law	-.107	.272	-.101	.827	-.117	-.034
temper tantrums	.109	.873	-.034	.327	-.012	-.046
inapprop. sex. behav.	.025	.391	-.094	.783	.029	-.117
fine motor skills	.645	-.058	.758	-.059	.386	.299
hearing	.048	.015	-.202	-.070	.566	.421
self preservation	.737	.162	.433	-.001	.450	.056

Extraction Method: Principal Component Analysis.
 Rotation Method: Promax with Kaiser Normalization.

The scree plot in Figure 2 again indicates that two components extract a large percentage of the underlying variance; however, there are still six components with eigenvalues greater than 1. Looking at the structure matrix in Table 9, Vision item now falls into a component by itself. Vision by itself also does not hold much interest for us in describing the relationship between disability, place of residence, and receipt of preventive care. We thus decided to drop the vision item and re-ran the factor analysis again. Results are as follows in Figure 3 and Table 10.

Figure 3. Scree plot, dropped Vision and Pica items, promax rotation ($\kappa=4$), principal components extraction method

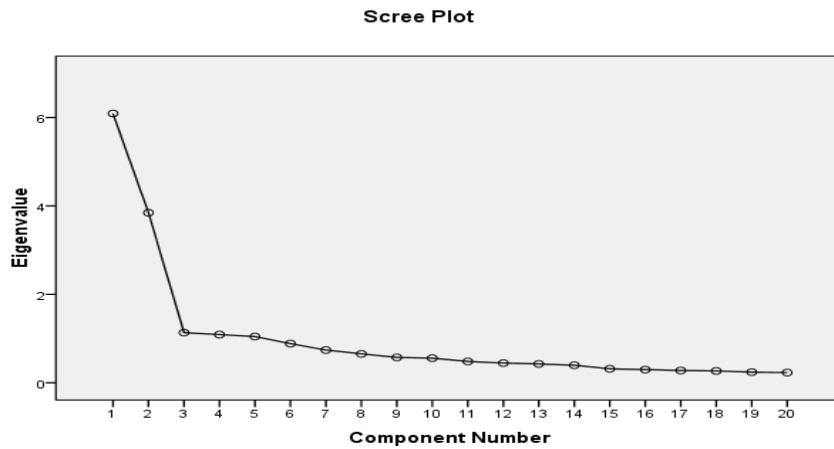


Table 10. Structure matrix, dropped Vision and Pica items, promax rotation ($\kappa=4$), principal components extraction method

	Component				
	1	2	3	4	5
mobility	.582	-.178	0.77	-.125	.324
express. commun.	.681	.016	.647	.010	0.7
seizures	.264	.059	0.71	-.029	.126
recept. commun.	.574	.042	.622	.055	0.78
self care	0.83	.113	.599	.007	.374
house managem.	0.84	.088	.545	.004	.342
money managem.	0.8	.104	.417	.013	.385
community living	0.84	.136	.370	.054	.281
leisure	0.83	.136	.402	.060	.304
injurious to self	.288	0.63	.187	.279	.276
runs away	.103	0.52	-.028	0.6	.085
aggress. phys.	.189	0.87	.035	.371	.089
aggress. verb.	-.031	0.8	-.157	.312	-.182
property destruct.	.153	0.8	.009	.411	.120
breaks law	-.115	.263	-.116	0.82	-.114
temper tantrums	.101	0.87	-.045	.321	-.022
inapprop. sex. behav.	.029	.386	-.105	0.78	-.002
fine motor skills	.641	-.053	0.8	-.048	.379
hearing	.087	.000	.014	-.035	0.72
self preservation	0.75	.166	.483	.021	.407

Extraction Method: Principal Component Analysis.
Rotation Method: Promax with Kaiser Normalization.

Similarly to previous runs, the scree plot in Figure 3 indicates that two components extract a large proportion of the variance. However, there are now five components with eigenvalues greater than 1. Furthermore, factor loadings in Table 10 give a sufficiently clear picture of which components the individual items fall into. We now need to interpret the resulting factor structure based on our assumptions and factor loadings.

Component 1 can be interpreted as the Functional Disability scale. In addition to the items proposed initially (independent living skills) it also contains self-preservation, but does not include mobility (as proposed before), which instead falls into Component 3 (Physical Disability). These seem like reasonable adjustments to the Functional Disability scale (self-preservation item seems to resemble some of the items in the Instrumental Activities of Daily Living (IADL) scale in addition to being phrased in terms of requiring assistance). Cronbach's Alpha for component 1 is 0.89.

Component 2 and Component 4 can be interpreted as the two subsets of Behavioral Disability measure. Component 4 seems to represent the behavioral items having possible legal repercussions, whereas Component 2 represents items without legal ramifications. It seems logical to maintain the two subsets as separate Behavioral Disability scales – Illegal Behavior Disability scale and Legal Behavior Disability scale. Cronbach's Alpha for Component 2 is 0.86 and for Component 4 is 0.60.

Component 5 confirms the a priori Communication Disability scale. We will thus retain the Communication Disability scale consisting of expressive and receptive communication items and hearing. Cronbach Alpha for Component 5 is 0.64.

Component 3 represents Physical Disability. It contains items proposed above (mobility, fine motor skills, seizures) with the exception of vision. For ease of distinguishing component 1 (Functional Disability) from component 3 (Physical Disability), Functional Disability will be referred to as ADL Disability, even though it does not closely correspond to the usual Activities of Daily Living scale. Cronbach Alpha for Component 3 is 0.72.

We next created disability scales by simply adding the rescaled component items, each with coefficient of 1, according to the structure suggested by the factor analysis. Adding the items together in such manner implicitly assigns equal weights (i.e. importance) to all items comprising the scale. So, for example, adding the rescaled scores for expressive communication, receptive communication and hearing to create the score for Communication disability assumes that receptive communication is as informative of this type of disability as expressive communication and hearing. We also calculated Cronbach Alphas for each resulting scale. Cronbach's Alpha is a statistic commonly used as a measure of internal consistency (reliability) of a measurement instrument or a scale. It measures how well a set of variables or items measures a single uni-dimensional latent construct. The Alphas are as follows: ADL (Functional) Disability scale: 0.89, Legal Behavior Disability scale: 0.86, Legal Behavior Disability scale: 0.60, Communication Disability scale: 0.64, and Physical Disability scale: 0.72. A Cronbach's Alpha of 0.7 or higher is usually sited as the acceptable cut-off for a set of items to be considered a good scale, but a value of 0.6 is also often sited as okay for an exploratory study such as this one. Figures 4 through 8 present histograms of distributions of scores of resulting disability scales.

Figure 4. Histogram of ADL disability scale (self-care+daily living skills/house mgmt+money management+community living+leisure/recreation+self-preservation). Range: 6-60.

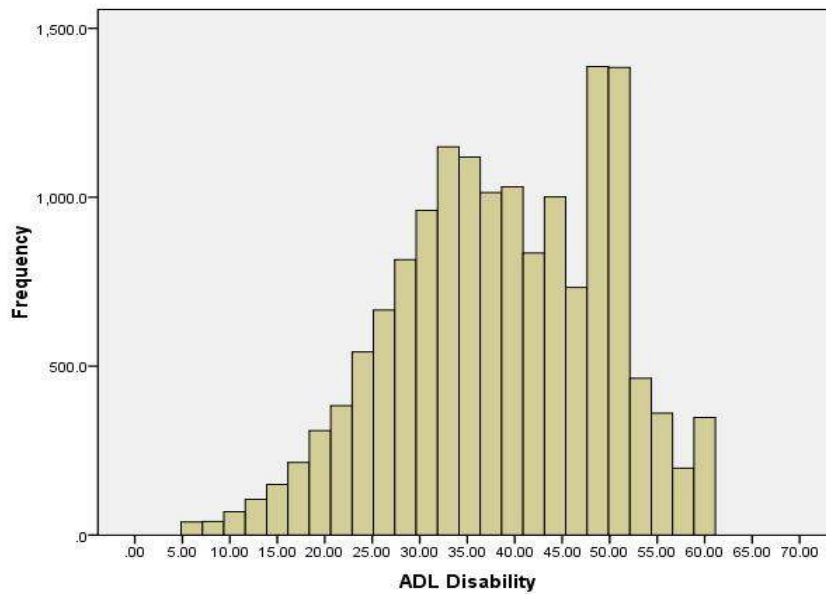


Figure 5. Histogram of Legal Behavior disability scale (injurious to self+physically aggressive+verbally aggressive+property destruction +temper outbursts). Range: 5-50.

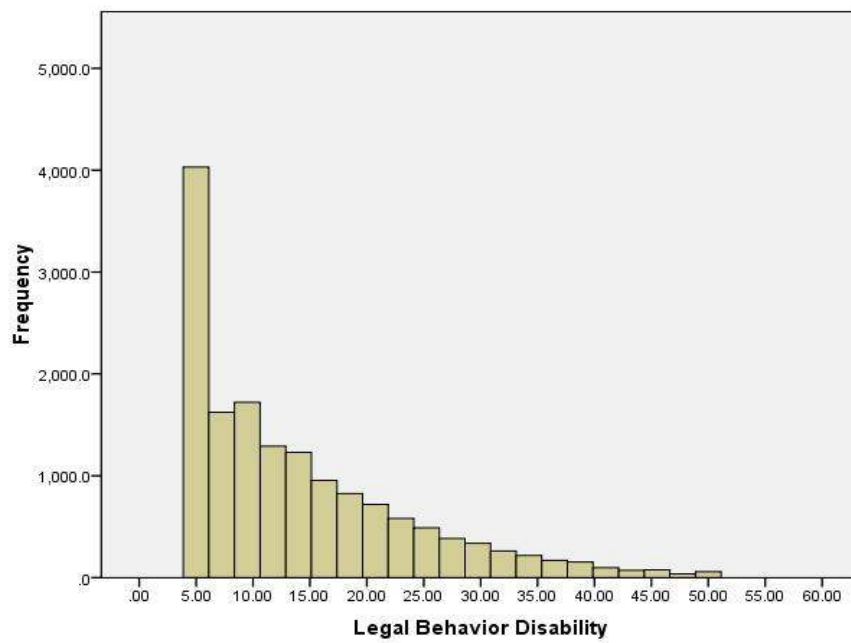


Figure 6. Histogram of Illegal Behavior disability scale (runs away+inappropriate sexual behavior+breaks law). Range 3-30.

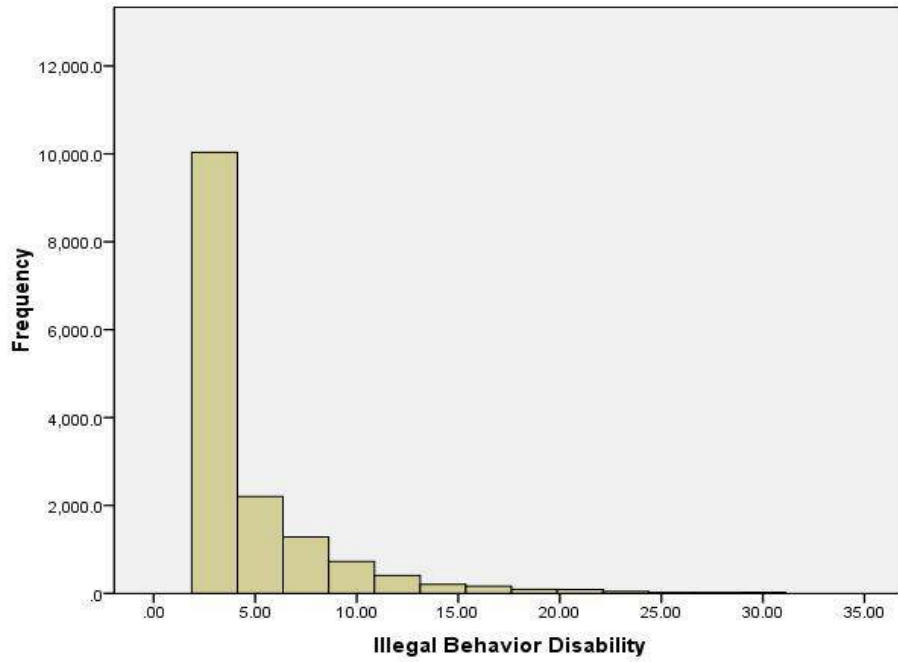


Figure 7. Histogram of Communication disability scale (expressive communication+receptive communication+hearing). Range: 3-30.

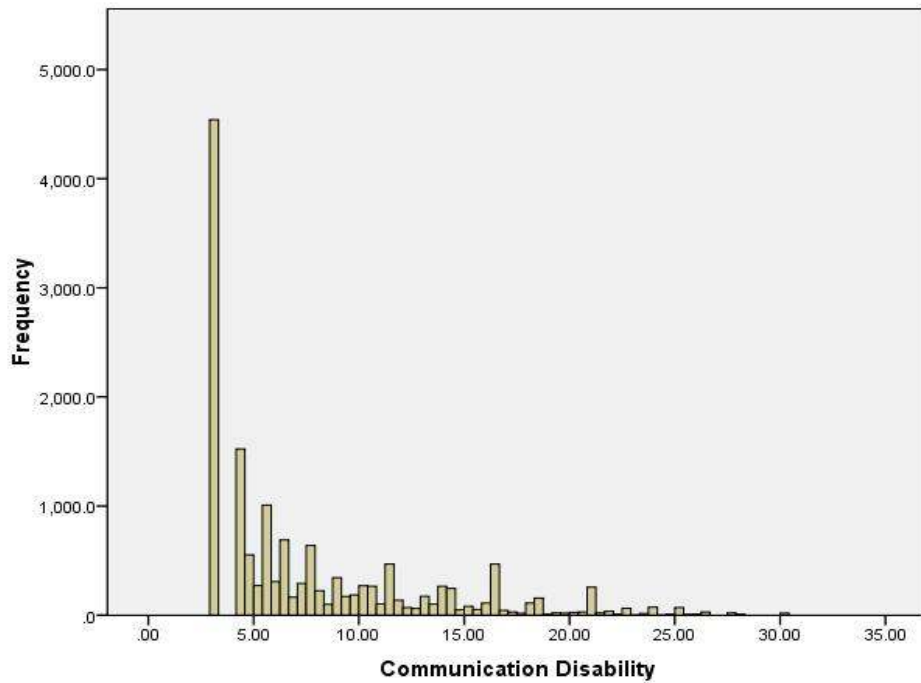
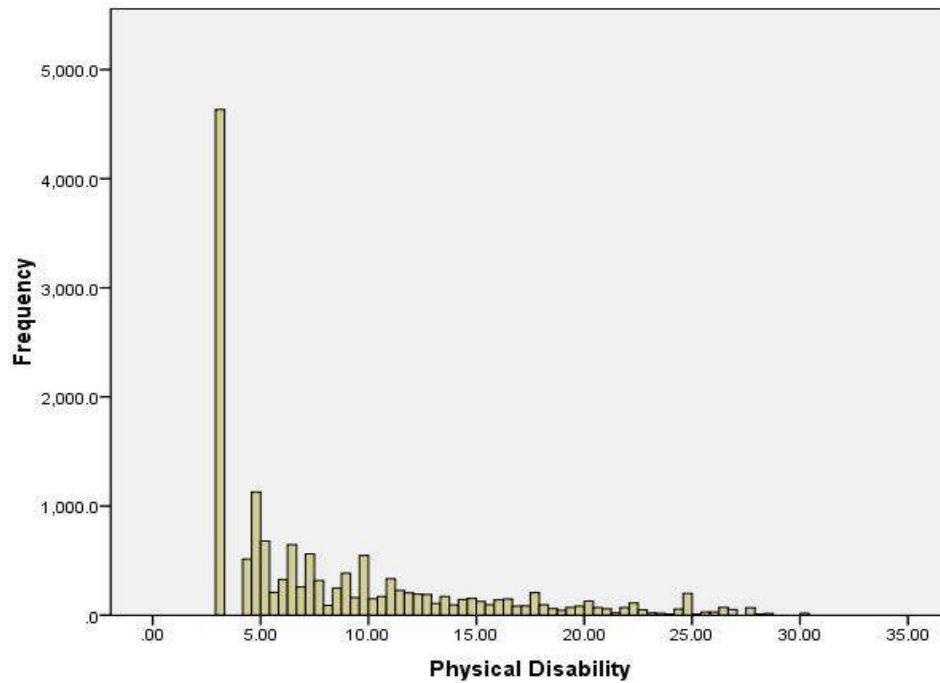


Figure 8. Histogram of Physical disability scale (mobility+seizures+fine motor skills). Range: 3-30.



There is a non-negligible amount of correlation between some of the disability scales. This is not surprising, considering that Promax rotation was used in factor analysis for extracting the components (allowing the components to correlate). Particularly high positive correlations are between physical and ADL disabilities, physical and communication disabilities, communication and ADL disabilities, and illegal and legal behavioral disabilities. Interestingly, there is a slight negative correlation between physical disability and both legal and illegal behavior disability, and between communication disability and illegal behavior disability. The correlations are presented in Table 11 below. As is evident from the table, the highest correlation between any two disability scales is around 0.6. This level of correlation is not likely to present problems in terms of multicollinearity when more than one or all disability scales

are included in a regression. The most conservative view is to assume multicollinearity when the correlation coefficient is above 0.5; usually, however, a coefficient of 0.7 or even 0.8 and above is taken to be indicative of multicollinearity. We may therefore feel relatively safe about interpreting individual disability coefficients in further analyses.

Based on insight stemming from conversations with people working in the field, we think that the level of disability of recipients with MR/DD has a non-linear relationship to the likelihood of their receiving preventive health care services. In fact, we think there may be a “threshold” effect – that is, the likelihood of having received preventive care drops once a certain level of disability is reached. In order to detect this threshold effect, we will transform the scales to form categorical variables as follows:

ADL disability – quartiles (so that approximately 25% of cases fall in each quartile),

Legal Behavior disability – quartiles,

Communication disability – quartiles,

Physical disability – quartiles,

Illegal Behavior disability – categories: None (=3), Mild (5.25-7.50),

Moderate/Severe (>7.50).

These categorical disability scales will be used in analyses examining the relationship between receipt of preventive care, place of residence, and disability (Hypotheses 6-10).

Table 11. Bivariate correlations between disability scales.

		Correlations				
		ADL Disab	Legal Behavior Disab	Illegal Behavior Disab	Communication Disab	Physical Disab
ADL Disab	Pearson Correlation	1	.181**	.022**	.588**	.606**
	Sig. (2-tailed)		.000	.006	.000	.000
	N	15319	15298	15282	14990	15161
Legal Behavior Disab	Pearson Correlation	.181**	1	.502**	.072**	-.026**
	Sig. (2-tailed)	.000		.000	.000	.001
	N	15298	15329	15299	15005	15172
Illegal Behavior Disab	Pearson Correlation	.022**	.502**	1	-.027**	-.120**
	Sig. (2-tailed)	.006	.000		.001	.000
	N	15282	15299	15315	14987	15156
Communication Disab	Pearson Correlation	.588**	.072**	-.027**	1	.489**
	Sig. (2-tailed)	.000	.000	.001		.000
	N	14990	15005	14987	15020	14881
Physical Disab	Pearson Correlation	.606**	-.026**	-.120**	.489**	1
	Sig. (2-tailed)	.000	.001	.000	.000	
	N	15161	15172	15156	14881	15192

** . Correlation is significant at the 0.01 level (2-tailed).

In addition, ICD-9 diagnoses codes as entered in the DD screening documents were used to create categorical Cognitive disability scale. These codes measure the level of mental retardation and are at least in part based on the person’s IQ level. There are 4 possible fields into which the ICD-9 diagnosis code can be entered. The codes of interest are: 317 – mild mental retardation, 318.0 – moderate mental retardation, 318.1 – severe mental retardation, 318.2 – profound mental retardation. One of the codes of interest could be found in one of the 4 possible diagnosis fields in all but 3.0% of assessments. The percentages of assessments (and persons) classified into mild, moderate, severe, or profound mental retardation based on the ICD-9 codes are given in Table 12. Our Cognitive disability scale will employ the same categories – Mild, Moderate, Severe, and Profound.

Table 12. Assessments classified according to level of mental retardation.

Level of mental retardation	Percentage
Mild	39.3%
Moderate	26.2%
Severe	17.0%
Profound	14.4%
Unknown	3.0%

Each person’s disabilities were measured based on his/her latest assessment during the two-year follow-up period.

Operationalizing preventive care

It is also necessary to operationalize “preventive care”. Many of recommended preventive health care services for the general population are directly applicable to the

MR/DD population. In addition, the Massachusetts Department of Mental Retardation of University of Massachusetts Medical School’s Center for Developmental Disabilities Evaluation and Research has modified some recommendations to specifically meet the health concerns of the population with MR/DD (Sep 2003). Their recommendations were based on the Massachusetts Health Quality Partnership Adult Preventive Care Recommendations together with Consensus Guidelines for Primary Health Care of Adults With Developmental Disabilities (Canadian Family Physician, Volume 52, 2006). Based on the general and modified preventive care guidelines, as well as data availability, the procedures in Table 13 were chosen as indicators of “preventive care”.

Table 13. Preventive health care procedures

<u>Procedure</u>	<u>Recommendation</u>	<u>Data Source</u>	<u>CPT or HCPCS Codes for 2001-02</u>
Outpatient office visit for general preventive medicine evaluation and management (physical exam)	1 every 12 months	Medicare and Medicaid	99381-99397
Oral health care – teeth cleaning	1 every 6 months	Medicaid	D1110, D1120, D1205
Vision test	1 every 12 months	Medicare and Medicaid	S0620-S0612, 92002-92371, 99172-99173
Hearing test	1 every 12 months	Medicare and Medicaid	V5008-V5011, 92551-92599
Influenza vaccine	1 every 12 months	Medicare and Medicaid	90657-90660, G0008
Cancer screening - papanicolaou test (for cervical cancer)	1 every 12 months when possible for women over 18 (guidelines vary, with women over 21	Medicare and Medicaid	- P3000, P3001, Q0091, G0141-G0148, 88150-88155, 88164-88167, 88141-88148

<ul style="list-style-type: none"> - fecal occult blood test (for colorectal cancer). 	<p>sometimes recommended; will use women over 18)</p> <p>1 every 12 months for men and women 50+</p>	<p>Medicare and Medicaid</p>	<p>- 82270, 82272, 82273, 82274, G0107, G0328</p>
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Each preventive procedure will be examined individually. Teeth cleaning will be examined over the course of 12 months to be consistent with other procedures and to facilitate creation of cumulative preventive measure (we performed sensitivity analysis with this outcome once every 6 months and the results were consistent). In addition, we created a cumulative preventive care measure. This cumulative preventive care measure was created by dividing the number of preventive procedures the person received over the course of 12 months by the number he/she was recommended to receive. Building the cumulative measure in this way implicitly assigns equal weights to each preventive procedure, thus implying that, for example, a hearing test is as important as an annual physical or a flu vaccine. While this assignment is somewhat arbitrary, there are no solid indications for whether and how different procedures should be valued differently. In the absence of good theory behind assigning different weights we chose to use our subjective judgment and assigned simple equal-weights to create the additive measure.

For each of the 15,352 people with DD screening assessments in 2001-2002, Medicaid and, if dual-eligible, Medicare utilization data were obtained for 2001-2002. The (action) date of latest DD screening assessment (which was used to calculate the level of disability and place of residence for each recipient) was compared with the date of each procedure in Medicaid and Medicare files. Procedures that were billed as having

taken place within 12 months prior to the date of latest DD screening assessment were searched for CPT or HCPCS codes corresponding to the preventive health service under investigation. A binary indicator variable was created for each preventive procedure. A person was defined as having had the procedure if one of the corresponding CPS/HCPCS codes was observed at least once during the person's observation period. A person was defined as not having had the procedure if the person appeared in the Medicaid/Medicare utilization files but one of the corresponding CPS/HCPCS codes was not observed during the person's observation period. If the person had no Medicaid/Medicare utilization records, he/she was assigned a missing for receipt of procedure and thus excluded from analyses involving preventive care and disability or preventive care and residence.

In order to control for the length of observation period during which a procedure could be observed in the utilization data, the MAX Personal Summary Record was used to calculate the number of months each person was eligible for Medicaid and Medicare in the 12 months of their look-back. Months of eligibility is an adjustor variable used in models as a proxy for the length of the observation period. As such, months of eligibility are expected to be positively related to the dependent variables in the models – the longer the observation period, the more chance there is of observing the outcome in the data. The first month available for look-back was January 2001, so if the date of a person's last DD assessment was prior to December 2002, then the maximum eligibility months were less than 12. For people who were also eligible for Medicare during the observation period, there was a very high correlation between the number of months they were eligible for Medicare and the number of months they were eligible for Medicaid (Pearson's $R=0.82$). Because of this high correlation, an indicator variable for dual

eligibility was created. 4,796 people (31%) were eligible only for Medicaid during their observation period, 10,145 (66%) were eligible for both Medicaid and Medicare during their observation period, 8 people (<1%) were eligible for Medicare only, 14 people (<1%) were eligible for neither Medicaid nor Medicare, and for 389 people (2%) Medicaid and Medicare eligibility could not be determined, in most cases because they were not found in Medicaid utilization files at all during the two years of available data.

Additional variables

Age and gender were extracted from DD screening assessments. Race was extracted from Medicaid data (Medicaid Analytic eXtract Person Summary files).

VI. Analysis and Results

Research question 1: How do level of different types of disabilities and receipt of preventive care vary across different residential arrangements for MR/DD adults receiving services in Minnesota? Of secondary interest are CDCS and SILS programs. An attempt will be made to investigate how disability differs for the participants of CDCS and SILS programs as opposed to non-participants.

Hypotheses 1-5

Hypothesis 1: Those MR/DD adults living in their own homes have a less severe level of cognitive and physical disabilities, fewer functional limitations and behavioral issues and higher communication ability than those in all other residential settings.

Hypothesis 2: Those living in family homes are younger and have fewer behavioral issues than those in foster/group homes and ICF/MRs.

Hypothesis 3: Those living in ICF/MRs are more disabled, both physically and cognitively, and have more behavioral issues than those in all other residential settings.

Table 14 presents means and standard deviations of disability scales created as described above for people in different residential arrangements, as well as percentage of people in those residential arrangements that fall into categorized disability scales (percentages may not add up to 100 because of missing data).

Table 14. Disability comparisons across residential arrangements.

Disability scale (range)	ICF-MR (mean/s.d.)	Family home (mean/s.d.)	Foster/group w/ staff (mean/s.d.)	Own home (mean/s.d.)	Other/unknown residence (mean/s.d.)
ADL disability (6-60)	44.8 / 7.8	36.8 / 10.8	39.2 / 9.7	25.0 / 9.1	40.3 / 14.0
Quartile 1	5.8%	33.0%	23.7%	78.0%	24.4%
Quartile 2	23.2%	30.4%	31.4%	17.3%	17.5%
Quartile 3	38.7%	22.4%	27.6%	3.7%	24.3%
Quartile 4	32.2%	14.0%	17.0%	1.0%	32.8%
Legal behavior disability (5-50)	15.7 / 9.5	11.5 / 8.4	16.0 / 10.2	9.5 / 6.0	13.9 / 10.6
Quartile 1	18.0%	37.7%	18.8%	42.5%	31.8%
Quartile 2	28.5%	31.6%	29.0%	35.7%	29.4%
Quartile 3	24.6%	15.0%	21.8%	15.2%	16.7%
Quartile 4	28.8%	15.4%	30.3%	6.7%	22.2%
Illegal behavior disability (3-30)	5.0 / 3.6	4.3 / 2.9	5.4 / 4.1	4.1 / 2.4	5.1 / 4.8
None	60.5%	74.6%	58.9%	75.6%	73.4%
Mild	27.4%	17.3%	26.1%	18.8%	13.6%
Mod/Severe	11.8%	7.8%	14.8%	5.6%	12.9%
Cognitive disability (ICD-9)	-	-	-	-	-
Mild	17.2%	41.7%	36.0%	79.3%	56.7%
Moderate	22.3%	33.4%	26.7%	12.8%	17.1%
Severe	26.1%	14.2%	19.0%	1.6%	12.5%
Profound	33.5%	6.3%	16.0%	0.3%	9.6%
Communication disability (3-30)	10.5 / 6.0	6.9 / 4.9	7.9 / 5.5	4.4 / 2.4	7.2 / 5.4

Quartile 1	12.8%	32.3%	27.9%	60.2%	34.8%
Quartile 2	16.2%	23.6%	23.2%	21.0%	18.6%
Quartile 3	22.5%	24.0%	22.5%	15.3%	21.4%
Quartile 4	45.5%	17.8%	25.2%	2.8%	19.4%
Physical disability (3-30)	10.6 / 6.7	7.8 / 5.8	8.1 / 5.8	5.3 / 3.4	10.2 / 6.7
Quartile 1	19.1%	32.6%	29.7%	51.0%	20.6%
Quartile 2	17.7%	24.9%	23.6%	25.5%	15.5%
Quartile 3	24.0%	20.1%	22.0%	15.9%	21.8%
Quartile 4	38.3%	21.4%	23.9%	7.4%	38.7%
Age	46.7 / 14.1	30.9 / 13.0	41.8 / 14.9	40.6 / 12.6	53.6 / 19.8
Percent female	45.7%	44.4%	43.3%	53.8%	49.1%
Race					
Percent white	95.6%	83.6%	93.9%	86.3%	85.8%
Percent nonwhite	4.1%	10.8%	5.2%	7.3%	9.7%
Percent unknown	0.4%	5.5%	0.9%	6.5%	4.5%
N	2,271	4,067	6,998	1,254	762

The mean ADL disability for those living in their own home is considerably lower (25.0 vs. 36.8 or higher) than the mean ADL disability for those living in any other residential arrangement. In addition, 78.0% of those living in their own home fall into the lowest ADL disability quartile versus 33.0% of those living in a family home, and 23.7% of those living in a foster home. Those living in an ICF-MR are more ADL disabled than those living in any other residential arrangement – average ADL disability score of 44.8 vs. 36.8 for those in family homes, 39.2 for those in foster homes, and 25.0 for those in own homes, and only 5.8% of those living in ICF-MRs fall into the lowest ADL disability quartile. Mean legal behavior disability is also slightly lower for those living in their own home (9.5 vs. 11.5 for those in a family home, and 16.0 for those in foster homes and 15.7 for those in ICF-MRs). Illegal behavior disability, however, looks approximately equal for those in own home and family home. Both legal and illegal behavioral disabilities levels seem to be similar in ICF-MR and foster home residents, although both score somewhat higher than those in family homes and own homes. Cognitive disability is lower for residents of their own home, with 79.3% being only mildly cognitively disabled, as compared to 36.0% of those in foster homes and 41.7% of those in family homes. Cognitive disability is higher for those in ICF-MRs, with 33.5% being classified as profoundly cognitively disabled, as compared to 16.0% or less for those in other residential arrangements. Communication disability for people in their own homes is lower as well, with both a lower mean score (mean score of 4.4 vs. 6.9 for those in a family home, 7.9 for those in a foster home and 10.5 for those in an ICF-MR) and a much higher percentage in lowest communication disability quartile (60.2% vs. 32.3% for those in family home, 27.9% for those in foster home, and 12.8% for those in

ICF-MR). For those living in ICF-MRs, communication disability is highest, with 45.5% falling in the most disabled communication disability quartile. Physical disability is on average only somewhat lower for those in their own home (mean of 5.3 vs. 7.8 for those in family home, 8.1 for those in foster homes and 10.6 for those in ICF-MR), but the difference in distribution of physical disability within residence types is more pronounced: only 7.4% of those living in their own home fall into the most disabled quartile vs. 21.4% of those in family homes, 23.9% of those in foster homes and 38.3% of those in ICF-MRs).

In general, there seems to be a consistent trend in that people living in their own home on average score lowest on disability scales (least disabled), followed by those living in family homes, foster homes, and ICF-MRs, in that order, with the exception being the behavior disability scales where residents of ICF-MRs and foster homes score approximately the same, and higher than residents of family homes. This trend supports the first three hypotheses.

In addition, people living in family home tend to on average be the youngest, while those living in ICF-MRs the oldest. Interestingly, a larger percentage of females live in their own homes than in other residential settings. A slightly smaller proportion of ICF-MR residents seem to be non-white, although it is difficult to draw conclusions with any certainty due to large amount of missing race data in some of the settings.

To formally test whether there are differences in disability scales between different residential arrangements, a simple one-way analysis of variance (ANOVA) can be performed for each continuous disability scale (all scales but cognitive disability). The purpose of an ANOVA is to test differences in means for people in different

residential arrangements for statistical significance by partitioning total variance into the component that is due to random error and the components that are due to differences between means.

Table 15 presents the results of the ANOVA with ADL disability as the dependent variable. The F-statistic is 854.551 and p-value is 0.000. The null hypothesis of no differences between means of different residential arrangements for ADL disability is rejected. Furthermore, it is possible to test whether there is a statistically significant difference in ADL disability between residents living in each pair of different residential arrangements. Table 16 presents these tests using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) in ADL disability between all possible pairs of residential arrangements (people in their own home are less ADL-disabled than people in a family home, a foster/group home, an ICF-MR, or other/unknown residence, people in a family home are less ADL-disabled than people in a foster/group home, an ICF-MR, or other/unknown residence, people living in a foster/group home are less ADL-disabled than people living in an ICF-MR, or other/unknown residence, and those living in an ICF-MR are more ADL-disabled than those living in other/unknown residence).

Table 15. ANOVA. ADL disability and residence

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	345793.385	4	86448.346	854.551	.000
Within Groups	1549200.179	15314	101.162		
Total	1894993.564	15318			

Table 16. Pairwise comparisons (with Bonferroni adjustment). ADL disability and residence.

(I) residence	(J) residence	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Own home	Other/unknown	-16.48001(*)	.46351	.000	-17.7813	-15.1787
	Foster/group home	-14.36141(*)	.30847	.000	-15.2274	-13.4954
	Family home	-12.05784(*)	.32497	.000	-12.9702	-11.1455
	ICF/MR	-20.03498(*)	.35389	.000	-21.0285	-19.0415
Foster/group home	Other/unknown	-2.11860(*)	.38555	.000	-3.2010	-1.0362
	Family home	2.30357(*)	.19855	.000	1.7462	2.8610
	ICF/MR	-5.67357(*)	.24300	.000	-6.3558	-4.9914
Family home	Other/unknown	-4.42217(*)	.39888	.000	-5.5420	-3.3023
	ICF/MR	-7.97714(*)	.26363	.000	-8.7173	-7.2370
ICF/MR	Other/unknown	3.55497(*)	.42277	.000	2.3681	4.7419

* The mean difference is significant at the .05 level.

Table 17 presents the results of the ANOVA with Legal Behavior disability as the dependent variable. The F-statistic is 237.387 and p-value is 0.000. The null hypothesis of no differences between means of different residential arrangements for legal behavioral disability is rejected. Table 18 presents the tests for statistically significant difference in legal behavior disability between different residential arrangements using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) between all possible pairs of residential arrangements, except for foster/group home vs. ICF-MR (people in their own home are less disabled than people in a family home, a foster/group home, an ICF-MR, or other/unknown residence,

people in a family home are less disabled than people in a foster/group home, an ICF-MR, or other/unknown residence, people living in a foster/group home are more disabled than those living in other/unknown residence, and those living in an ICF-MR are more disabled than those living in other/unknown residence).

Table 17. ANOVA. Legal Behavior disability and residence

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	83943.115	4	20985.779	237.387	.000
Within Groups	1354692.587	15324	88.403		
Total	1438635.701	15328			

Table 18. Pairwise comparisons (with Bonferroni adjustment). Legal Behavior disability and residence.

(I) residence	(J) residence	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower	Upper
					Bound	Bound
Own home	Other/unknown	-4.26649(*)	.43194	.000	-5.4791	-3.0539
	Foster/group home	-6.45031(*)	.28845	.000	-7.2601	-5.6405
	Family home	-1.94580(*)	.30389	.000	-2.7990	-1.0926
	ICF/MR	-6.06398(*)	.33090	.000	-6.9930	-5.1350
Foster/group home	Other/unknown	2.18382(*)	.35870	.000	1.1768	3.1908
	Family home	4.50451(*)	.18560	.000	3.9835	5.0256
	ICF/MR	.38633	.22715	.890	-.2514	1.0240
Family home	Other/unknown	-2.32069(*)	.37123	.000	-3.3629	-1.2785
	ICF/MR	-4.11818(*)	.24645	.000	-4.8101	-3.4263
ICF/MR	Other/unknown	1.79749(*)	.39365	.000	.6923	2.9026

* The mean difference is significant at the .05 level.

Table 19 presents the results of the ANOVA with Illegal Behavior disability as the dependent variable. The F-statistic is 74.762 and p-value is 0.000. The null hypothesis of no differences between means of different residential arrangements for illegal behavioral disability is rejected. Table 20 presents the tests for statistically significant difference in illegal behavioral disability between those living in different possible residential arrangements using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) in illegal behavior disability between all possible pairs of residential arrangements, except for own home vs. family home, foster/group home vs. other/unknown, and ICF-MR vs. other/unknown (people in their own home are less disabled than people in a foster/group home, an ICF-MR, or other/unknown residence, people in a family home are less disabled than people in a foster/group home, an ICF-MR, or other/unknown residence, and people living in a foster/group home are more disabled than people living in an ICF-MR). The fact that people in foster/group homes are more than or as disabled in terms of both legal and illegal behaviors than people in ICF-MRs and/or other/unknown residence may be due to the fact that both behavioral scales contain items that measure only behaviors actually observed. In both ICF-MRs and SNFs (as an example of other residence), there may be less of an opportunity to physically engage in behaviors measured by the scale items, which would lead to a lower disability score.

Table 19. ANOVA. Illegal Behavior disability and residence.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	4031.025	4	1007.756	74.762	.000
Within Groups	206372.486	15310	13.480		
Total	210403.512	15314			

Table 20. Pairwise comparisons (with Bonferroni adjustment). Illegal Behavior disability and residence.

(I) residence	(J) residence	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Own home	Other/unknown	-.96201(*)	.16881	.000	-1.4359	-.4881
	Foster/group home	-1.31257(*)	.11276	.000	-1.6291	-.9960
	Family home	-.22032	.11878	.636	-.5538	.1131
	ICF/MR	-.93643(*)	.12936	.000	-1.2996	-.5732
Foster/group home	Other/unknown	.35056	.14015	.124	-.0429	.7440
	Family home	1.09225(*)	.07249	.000	.8887	1.2957
	ICF/MR	.37614(*)	.08878	.000	.1269	.6254
Family home	Other/unknown	-.74169(*)	.14504	.000	-1.1489	-.3345
	ICF/MR	-.71611(*)	.09631	.000	-.9865	-.4457
ICF/MR	Other/unknown	-.02558	.15383	1.000	-.4575	.4063

* The mean difference is significant at the .05 level.

Table 21 presents the results of the ANOVA with Communication disability as the dependent variable. The F-statistic is 313.646 and p-value is 0.000. The null hypothesis of no differences between means of different residential arrangements for

communication disability is rejected. Table 22 presents the tests for statistically significant differences in communication disability between different residential arrangements using Bonferroni correction for multiple comparisons. There are statistically significant differences in communication disability between all possible pairs of residential arrangements, except for family home vs. other/unknown (people in their own home are less disabled than people in a family home, a foster/group home, an ICF-MR, or other/unknown residence, people in a family home are less disabled than people in a foster/group home, or an ICF-MR, people living in a foster/group home are less disabled than people living in an ICF-MR, and slightly more disabled than those living in other/unknown residence, and those living in an ICF-MR are more disabled than those living in other/unknown residence).

Table 21. ANOVA. Communication disability and residence

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	34101.927	4	8525.482	313.646	.000
Within Groups	408135.379	15015	27.182		
Total	442237.306	15019			

Table 22. Pairwise comparisons (with Bonferroni adjustment). Communication disability and residence.

(I) residence	(J) residence	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Own home	Other/unknown	-2.82208(*)	.24432	.000	-3.5080	-2.1362
	Foster/group home	-3.48921(*)	.16057	.000	-3.9400	-3.0384
	Family home	-2.54078(*)	.16933	.000	-3.0162	-2.0654

	ICF/MR	-6.14535(*)	.18484	.000	-6.6643	-5.6264
Foster/group home	Other/unknown	.66712(*)	.20447	.011	.0931	1.2412
	Family home	.94843(*)	.10388	.000	.6568	1.2401
	ICF/MR	-2.65614(*)	.12761	.000	-3.0144	-2.2979
Family home	Other/unknown	-.28131	.21142	1.000	-.8749	.3122
	ICF/MR	-3.60458(*)	.13847	.000	-3.9933	-3.2158
ICF/MR	Other/unknown	3.32327(*)	.22403	.000	2.6943	3.9522

* The mean difference is significant at the .05 level.

Table 23 presents the results of the ANOVA with Physical disability as the dependent variable. The F-statistic is 207.102 and p-value is 0.000. The null hypothesis of no differences between means of different residential arrangements for physical disability is rejected. Table 24 presents the tests for statistically significant difference in physical disability between different residential arrangements using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) in physical disability between all possible pairs of residential arrangements, except for ICF-MR vs. other/unknown and foster/group home vs. family home (people in their own home are less physically-disabled than people in a family home, a foster/group home, an ICF-MR, or other/unknown residence, people in a family home are less physically-disabled than people in an ICF-MR, or other/unknown residence, and people living in a foster/group home are less physically-disabled than people living in an ICF-MR).

Table 23. ANOVA. Physical disability and residence

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	29742.059	4	7435.515	207.102	.000
Within Groups	545253.263	15187	35.903		

Total	574995.323	15191			
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Table 24. Pairwise comparisons (with Bonferroni adjustment). Physical disability and residence.

(I) residence	(J) residence	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Own home	Other/unknown	-5.43570(*)	.27843	.000	-6.2174	-4.6540
	Foster/group home	-2.92508(*)	.18419	.000	-3.4422	-2.4080
	Family home	-2.65489(*)	.19406	.000	-3.1997	-2.1101
	ICF/MR	-5.47734(*)	.21143	.000	-6.0709	-4.8838
Foster/group home	Other/unknown	-2.51062(*)	.23230	.000	-3.1628	-1.8585
	Family home	.27020	.11873	.229	-.0631	.6035
	ICF/MR	-2.55226(*)	.14539	.000	-2.9604	-2.1441
Family home	Other/unknown	-2.78081(*)	.24020	.000	-3.4552	-2.1065
	ICF/MR	-2.82246(*)	.15771	.000	-3.2652	-2.3797
ICF/MR	Other/unknown	.04164	.25444	1.000	-.6727	.7560

* The mean difference is significant at the .05 level.

One-way analysis of variance formally confirmed our hypothesis that adults with developmental disabilities who live in their own homes have less severe levels of disabilities than people living in all other settings. Furthermore, the hypothesis that adults living in family homes have fewer behavioral issues than adults living in foster/group homes and ICF/MRs was confirmed as well. In addition, residents of family homes were shown to also be less disabled in terms of ADL and communication disability than residents of foster/group homes and ICF/MRs. Finally, analysis of variance formally tested whether ICF/MR residents are, in fact, significantly more

disabled than residents of any other setting. This hypothesis was confirmed for all types of disabilities except behavior disabilities.

Hypothesis 4: Those MR/DD adults in SILS program have a less severe level of cognitive and physical disabilities, fewer functional limitations, fewer behavioral issues and higher communication ability than those who are in CDCS program or who are not in either program.

Table 25 presents means and standard deviations of disability scales for people in different programs, as well as percentage of people in those programs that fall into categorized disability scales (percentages may not add up to 100 because of missing data).

Table 25. Disability scales across programs.

Disability scale (range)	CDCS (mean/s.d.)	SILS (mean/s.d.)	Neither/Unknown (mean/s.d.)
ADL disability (7-70)	38.0 / 10.3	22.6 / 7.9	39.2 / 10.9
Quartile 1	29.1%	89.2%	25.6%
Quartile 2	32.2%	7.8%	28.4%
Quartile 3	24.2%	2.2%	26.8%
Quartile 4	14.4%	0.4%	19.0%
Legal behavioral disability (6-60)	13.0 / 9.5	8.9 / 5.8	14.4 / 9.8
Quartile 1	31.6%	48.3%	24.9%
Quartile 2	31.9%	34.2%	29.9%
Quartile 3	15.1%	12.7%	20.4%
Quartile 4	21.1%	4.9%	24.8%
Illegal behavioral disability (2-20)	4.7 / 3.6	3.8 / 2.3	5.0 / 3.8
None	70.1%	81.0%	64.4%
Mild	18.5%	14.5%	23.5%
Mod/Severe	11.0%	4.5%	12.0%
Cognitive disability (ICD-9)	-	-	-

Mild	44.1%	83.6%	37.2%
Moderate	32.1%	10.2%	26.1%
Severe	12.4%	1.0%	18.1%
Profound	7.1%	0.0%	15.8%
Communication disability (2-20)	7.1 / 4.9	4.1 / 2.2	7.9 ± 5.5
Quartile 1	30.2%	67.7%	28.1%
Quartile 2	23.6%	17.8%	21.8%
Quartile 3	25.2%	12.5%	22.3%
Quartile 4	19.0%	1.8%	25.5%
Physical disability (3-30)	8.6 ± 6.1	4.9 / 2.9	8.5 ± 6.2
Quartile 1	26.9%	56.9%	29.6%
Quartile 2	25.0%	21.5%	22.6%
Quartile 3	21.7%	16.4%	21.4%
Quartile 4	25.3%	4.9%	25.3%
Age	31.0 / 12.2	39.2 / 12.7	41.2 / 15.8
Percent female	45.9%	53.6%	44.7%
Race			
Percent white	85.1%	78.1%	91.4%
Percent nonwhite	11.9%	7.6%	6.4%
Percent unknown	3.0%	14.3%	2.2%
N	1,459	489	13,404

The mean ADL disability score for those in SILS program is considerably lower than for those in CDCS program or those in neither program (22.61 vs. 38.05 for those in CDCS and 39.2 for those in neither), with almost 90% falling in the lowest ADL disability quartile. Both legal and illegal behavior disability scores are also somewhat lower for SILS program participants (mean 8.9 legal behavioral disability score for those in SILS vs. 13.0 for those in CDCS and 14.4 for those in neither and mean 3.8 illegal behavioral disability score for those in SILS vs. 4.7 for those in CDCS and 5.0 for those in neither). There are no profoundly cognitively disable people in SILS program, as compared to 7.1% profoundly disabled in CDCS program and 15.8% in neither. 83.6%

of those in SILS program are mildly cognitively disabled, as compared to 44.1% of those in CDCS program and only 37.2% of those in neither program. Mean communication disability is also lower for those in SILS (4.1 vs. 7.1 for those in CDCS and 7.9 for those in neither program). On average, physical disability score for those in SILS program is also lower than those in CDCS or neither program, with only a small percentage of recipients falling into the most disabled quartile (4.9% for SILS participants vs. 25.3% for both CDCS participants and for those in neither program). Hypothesis 4 is thus supported by descriptive analysis.

In addition, people enrolled in the CDCS program tended to on average be younger than those participating in the SILS program or not participating in either program. A larger percentage of females seem to be participating in the SILS program than in CDCS or neither program. It is difficult to draw conclusions about program participation by race due to large amount of missing data.

As with residential arrangements, to formally test whether there are differences in disability scales between different programs, a simple one-way analysis of variance (ANOVA) can be performed for each continuous disability scale.

Table 26 presents the results of the ANOVA with ADL disability as the dependent variable. The F-statistic is 569.498 and p-value is 0.000. The null hypothesis of no differences between means of participants of different programs for ADL disability is rejected. Table 27 presents the tests for statistically significant difference in ADL disability between those in CDCS, SILS and neither/unknown using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) in ADL disability between all possible pairs of programs (those in CDCS

are more ADL-disabled than those in SILS program and less ADL-disabled than those in neither program, and those in SILS are less ADL-disabled than those in neither program).

Table 26. ANOVA. ADL disability and programs.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	131169.316	2	65584.658	569.498	.000
Within Groups	1763824.249	15316	115.162		
Total	1894993.564	15318			

Table 27. Pairwise comparisons (with Bonferroni adjustment). ADL disability and programs.

(I) program	(J) program	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
SILS	CDCS	-15.47390(*)	.56166	.000	-16.8186	-14.1292
	Neither	-16.67585(*)	.49506	.000	-17.8611	-15.4906
CDCS	Neither	-1.20194(*)	.29597	.000	-1.9106	-.4933

* The mean difference is significant at the .05 level.

Table 28 presents the results of the ANOVA with Legal Behavior disability as the dependent variable. The F-statistic is 87.413 and p-value is 0.000. The null hypothesis of no differences between means of different program participants for legal behavior disability is rejected. Table 29 presents the tests for statistically significant difference in legal behavioral disability between those in CDCS, SILS and neither/unknown using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) in legal behavior disability between all possible pairs of programs (those in CDCS are more disabled than those in SILS program and less

disabled than those in neither program, and those in SILS are less disabled than those in neither program).

Table 28. ANOVA. Legal Behavior disability and programs.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	16225.726	2	8112.863	87.413	.000
Within Groups	1422409.975	15326	92.810		
Total	1438635.701	15328			

Table 29. Pairwise comparisons (with Bonferroni adjustment). Legal Behavior disability and programs.

(I) program	(J) program	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
SILS	CDCS	-4.17392(*)	.50361	.000	-5.3797	-2.9681
	Neither	-5.53295(*)	.44354	.000	-6.5949	-4.4710
CDCS	Neither	-1.35904(*)	.26602	.000	-1.9959	-.7221

* The mean difference is significant at the .05 level.

Table 30 presents the results of the ANOVA with Illegal Behavior disability as the dependent variable. The F-statistic is 24.817 and p-value is 0.000. The null hypothesis of no differences between means of different program participants for illegal behavior disability is rejected. Table 31 presents the tests for statistically significant difference in illegal behavioral disability those in CDCS, SILS and neither/unknown using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.02 for CDCS vs. neither and p-value=0.000 for SILS vs. neither and SILS vs. CDCS) in legal behavioral disability between all possible pairs of programs (those in CDCS are slightly more disabled than those in SILS program and less disabled

than those in neither program, and those in SILS are less disabled than those in neither program).

Table 30. ANOVA. Illegal Behavior disability and programs.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	679.811	2	339.906	24.817	.000
Within Groups	209723.700	15312	13.697		
Total	210403.512	15314			

Table 31. Pairwise comparisons (with Bonferroni adjustment). Illegal Behavior disability and programs.

(I) program	(J) program	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
SILS	CDCS	-.85515(*)	.19348	.000	-1.3184	-.3919
	Neither	-1.13289(*)	.17039	.000	-1.5408	-.7249
CDCS	Neither	-.27773(*)	.10223	.020	-.5225	-.0330

* The mean difference is significant at the .05 level.

Table 32 presents the results of the ANOVA with Communication disability as the dependent variable. The F-statistic is 126.066 and p-value is 0.000. The null hypothesis of no differences in terms of communication disability is rejected. Table 33 presents the tests for statistically significant difference in communication disability between those in CDCS, SILS and neither/unknown using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) in communication disability between all possible pairs of programs (those in CDCS are more disabled than those in SILS program and less disabled than those in neither program, and those in SILS are less disabled than those in neither program).

Table 32. ANOVA. Communication disability and programs.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	7302.433	2	3651.216	126.066	.000
Within Groups	434934.873	15017	28.963		
Total	442237.306	15019			

Table 33. Pairwise comparisons (with Bonferroni adjustment). Communication disability and programs.

(I) program	(J) program	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
SILS	CDCS	-3.03470(*)	.28219	.000	-3.7103	-2.3591
	Neither	-3.79955(*)	.24811	.000	-4.3936	-3.2055
CDCS	Neither	-.76485(*)	.14997	.000	-1.1239	-.4058

* The mean difference is significant at the .05 level.

Lastly, table 34 presents the results of the ANOVA with Physical disability as the dependent variable. The F-statistic is 82.094 and p-value is 0.000. The null hypothesis of no differences between means of different program participants for physical disability is rejected. Table 35 presents the tests for statistically significant difference in physical disability between those in CDCS, SILS and neither/unknown using Bonferroni correction for multiple comparisons. There are statistically significant differences (p-value=0.000) between SILS participants and CDCS participants and between SILS participants and those not participating in either program (SILS participants are less disabled than both), but no statistically significant differences between CDCS participants and those not participating in either program.

Table 34. ANOVA. Physical disability and programs.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	6149.015	2	3074.508	82.094	.000
Within Groups	568846.307	15189	37.451		
Total	574995.323	15191			

Table 35. Pairwise comparisons (with Bonferroni adjustment). Physical disability and programs.

(I) program	(J) program	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
SILS	CDCS	-3.63793(*)	.32071	.000	-4.4058	-2.8701
	Neither	-3.60849(*)	.28236	.000	-4.2845	-2.9325
CDCS	Neither	.02944	.16964	1.000	-.3767	.4356

* The mean difference is significant at the .05 level.

One-way analysis of variance formally confirmed our hypothesis that adults with developmental disabilities who were enrolled in the SILS program have less severe levels of disabilities than people who participated in the CDCS program or were not enrolled in either program.

Hypothesis 5: Those living in foster/group homes who are in the CDCS program are younger, less cognitively and physically disabled, with fewer behavioral issues and functional limitations and with higher communication ability than residents of foster/group homes who are not in CDCS (or SILS) program.

Table 36 presents average age, means and standard deviations of disability scales created as described above for people in different residential arrangement and program combinations, as well as percentage of people in those combinations that fall into categorized disability scales (percentages may not add up to 100 because of missing data).

Foster/group home residents in CDCS program score slightly lower on ADL disability scale (average score of 37.1 vs. 39.6 for foster/group home residents not in CDCS or SILS). They also score lower on communication disability scale (mean score of 6.7 vs. 7.9). A considerably larger percentage of foster/group home residents who are in the CDCS program are only mildly cognitive disabled than of foster/group home residents not in CDCS (or SILS) program (47.8% vs. 35.3%). On both Behavior disability scales, as well as the Physical disability scale, however, there does not seem to be a real difference between foster/group home residents who were and were not enrolled in the CDCS program. With the exception of Behavior disability and Physical disability, then, hypothesis 5 is supported by descriptive analysis. Foster/group home residents who are in the CDCS program tend to be younger than foster/group home residents who are not in CDCS (or SILS).

Table 36. Disability scales across residence/program combinations.

	ICF-MR (mean/s.d.)	SILS			CDCS			Neither / Unknown		
		Family home (mean/s.d.)	Foster/ group home (mean/s.d.)	Own home (mean/s.d.)	Family home (mean/s.d.)	Foster/ group home (mean/s.d.)	Own home (mean/s.d.)	Family home (mean/s.d.)	Foster/ group home (mean/s.d.)	Own home (mean/s.d.)
ADL disability (7-70)	45.1 / 8.0	25.7 / 8.9	28.3 / 6.8	22.0 / 7.5	39.5 / 10.2	37.1 / 9.4	29.7 / 9.0	36.7 / 11.0	39.6 / 9.8	25.8 / 9.3
Quartile 1	5.8%	79.3%	66.7%	92.1%	25.1%	28.7%	60.5%	34.3%	23.4%	74.3%
Quartile 2	23.2%	11.0%	33.3%	5.6%	30.6%	37.3%	31.5%	30.8%	31.1%	20.4%
Quartile 3	38.7%	14.6%	0.0%	1.7%	27.0%	23.1%	5.6%	21.3%	27.9%	4.4%
Quartile 4	32.2%	0.0%	0.0%	0.6%	17.2%	10.8%	2.4%	13.3%	17.4%	0.9%
Legal behav. dis. (6-60)	15.6 / 9.5	9.6 / 7.9	14.3 / 11.1	8.6 / 5.1	12.2 / 9.0	16.3 / 10.7	11.1 / 8.4	11.3 / 8.1	16.0 / 10.2	9.7 / 6.0
Quartile 1	18.0%	47.6%	22.2%	48.6%	34.7%	19.4%	37.9%	38.4%	18.8%	40.3%
Quartile 2	28.5%	34.1%	33.3%	34.3%	32.7%	28.7%	35.5%	31.2%	29.0%	36.3%
Quartile 3	24.6%	11.0%	22.2%	12.9%	14.1%	18.2%	14.5%	15.4%	22.0%	16.3%
Quartile 4	28.8%	7.3%	22.2%	4.2%	18.0%	33.6%	12.1%	14.8%	30.1%	7.0%
Illegal beh. dis. (2-20)	5.0 / 3.6	4.2 / 3.0	6.5 / 6.2	3.7 / 1.9	4.4 / 3.1	5.8 / 4.9	4.6 / 2.7	4.3 / 2.9	5.4 / 4.1	4.2 / 2.6
None	60.5%	76.8%	66.7%	83.4%	74.6%	59.0%	62.9%	74.6%	58.9%	73.6%
Mild	27.4%	15.9%	0.0%	13.8%	16.0%	22.2%	28.2%	17.7%	26.3%	19.5%
Mod/ Sev	11.8%	7.3%	33.3%	2.8%	8.9%	18.5%	8.9%	7.4%	14.6%	6.3%
Cognitive dis. (ICD-9)	-	-	-	-	-	-	-	-	-	-
Mild	17.2%	74.4%	88.9%	86.2%	38.5%	47.8%	74.2%	41.9%	35.3%	77.0%
Moderate	22.3%	19.5%	0.0%	8.1%	35.8%	29.0%	12.9%	33.0%	26.6%	15.0%

Severe	26.1%	2.4%	0.0%	0.8%	13.6%	12.3%	4.0%	14.7%	19.3%	1.6%
Profound	33.5%	0.0%	0.0%	0.0%	6.9%	8.0%	2.4%	6.3%	16.4%	0.1%
Communication disability (2-20)	10.5 / 6.0	4.4 / 3.7	4.1 / 2.6	4.0 / 1.8	7.5 / 5.1	6.7 / 5.0	5.1 / 2.8	6.8 / 4.8	7.9 / 5.5	4.4 / 2.5
Quartile 1	12.8%	63.4%	77.8%	67.7%	25.9%	36.4%	46.0%	33.5%	26.9%	59.0%
Quartile 2	16.2%	23.2%	11.1%	17.1%	22.9%	23.5%	29.0%	23.9%	23.2%	21.4%
Quartile 3	22.5%	9.8%	0%	14.0%	28.1%	19.8%	16.9%	23.0%	22.7%	15.6%
Quartile 4	45.5%	2.4%	11.1%	1.1%	20.5%	19.1%	7.3%	17.3%	25.5%	2.8%
Physical disability (3-30)	10.8 / 6.9	5.1 / 3.0	4.5 / 2.0	4.9 / 3.0	9.0 / 6.3	8.1 / 5.8	6.4 / 4.3	7.7 ± 5.9	8.2 / 5.9	5.4 / 3.4
Quartile 1	19.1%	52.4%	55.6%	59.4%	25.0%	29.6%	33.1%	34.5%	29.7%	50.0%
Quartile 2	17.7%	25.6%	22.2%	20.8%	24.1%	24.7%	34.7%	25.1%	23.6%	26.0%
Quartile 3	24.0%	14.6%	22.2%	14.9%	21.0%	23.5%	21.8%	20.0%	22.0%	15.4%
Quartile 4	38.3%	7.3%	0.0%	4.8%	28.6%	21.3%	10.5%	19.4%	23.8%	8.1%
Age	46.7 / 14.1	31.9 / 12.4	32.2 / 16.3	40.5 / 11.9	28.4 / 10.7	35.8 / 13.4	38.5 / 13.3	31.7 / 13.5	42.1 / 14.9	41.0 / 12.8
Percent female	45.7%	47.6%	33.3%	54.5%	46.3%	43.5%	48.4%	43.7%	43.3%	54.4%
Race										
% white	95.6%	64.6%	88.9%	82.6%	82.6%	92.6%	87.1%	84.5%	93.9%	87.9%
% nonwhite	4.1%	9.8%	11.1%	5.3%	13.9%	6.5%	8.9%	9.8%	5.2%	7.9%
% unknown	0.4%	25.6%	0%	12.1%	3.5%	0.9%	4.0%	5.7%	0.9%	4.3%
N	2,271	82	9	356	1,000	324	124	2,985	6,665	774

Analogously to formal one-way ANOVA analysis for residence and program, two-way ANOVAs and pairwise comparisons were performed for residence/program combinations. In the interest of saving space, the tables are not shown. However, the hypothesis that foster/group home residents participating in CDCS program are less disabled than foster/group home residents who do not participate in either CDCS (or SILS) program is supported for ADL and communication disability, though not for either behavior disability or physical disability. Furthermore, some additional interesting observations emerged. Specifically, those living in their own home who are on the CDCS program are more ADL disabled than those living in their own home who are not in either CDCS (or SILS). The same is true for people living in a family home who are on the CDCS program vs. those living in a family home who are not in either CDCS (or SILS), both in terms of Physical and ADL disabilities. One possible explanation for this may be that participating in the CDCS program allows more disabled people to remain in their own or family home by managing and directing their staff and care resources better, instead of being placed in more staff-intensive residential arrangements.

It may also be of interest to see if there are differences in disability as well as residence and program participation for MR/DD consumers of different ages. Some descriptive analyses of differences by age are presented in Appendix 3.

Hypotheses 6-11

Hypothesis 6: The more physically and cognitively disabled MR/DD adults are less likely to receive preventive care, controlling for other factors.

Hypothesis 7: MR/DD adults with more communication skills/ability are more likely to receive preventive care, controlling for other factors.

Table 37 gives the overall proportion of people in our sample who have received the preventive services in previous 12 months. Fecal occult blood test may present problems in terms of power due to the small number of people who are recommended the test in the sample.

Table 37. Proportion receiving individual preventive procedures

	Received	Did not receive	Unable to assign
Physical exam (n=15,352)	45.0%	53.3%	1.7%
Dental cleaning (n=15,352)	57.9%	40.4%	1.8%
Vision test (n=15,352)	42.9%	55.4%	1.7%
Hearing test (n=15,352)	15.5%	82.8%	1.7%
Flu vaccine (n=15,352)	25.4%	72.9%	1.7%
Pap smear (n=6,767)	18.1%	80.1%	1.8%
Fecal occult blood test (n=3,756)	8.8%	90.1%	1.0%

As is evident from the table, the percentage of people receiving recommended procedures varies from about 9% to 58%. The highest “compliance” rate is for dental cleaning, with 57.9% of the sample having received the cleaning in the 12 months of observation. Next is physical exam and vision test, with 45.0% and 42.9% respectively. Fecal occult blood test and hearing test had lowest “compliance” rate, with only 8.8% and 15.5% of the sample having received the respective procedures. The receipt of procedures could not be ascertained for 1.0-1.8% of the sample, in most cases due to recipients not being eligible for Medicaid during the observation period.

Physical exam

Table 38 presents the results of logistic regressions with physical exam as dependent variable. Rows 1 through 6 are models examining whether the probability of having a physical exam in the last 12 months is affected by recipient’s disability, controlling for months of Medicaid eligibility, dual eligibility status, age, gender, and race.

The largest effect in terms of odds ratios is by the level of ADL and Physical disabilities. As is evident from the table, however, the effect is non-linear - the odds of having had a physical exam in the previous 12 months are 1.3 or 1.4 times higher for a person in one of three lower ADL disability quartiles than they are for a person in the highest quartile. It appears that being the most ADL disabled lowers the probability of having the exam, with no significant differences between other levels of ADL disability. The pattern is the same for physical disability – the odds of having the exam are about 1.35 to 1.5 for those in two lower disability quartiles as compared to those in the two

most physically disabled quartiles. Communication and cognitive disability seem to not affect the odds of having had the exam. Being less disabled in terms of both legal and illegal behavior disability, on the other hand, actually seems to lessen the probability of having had a physical exam in the previous 12 months. The odds of having the exam are 0.7 for those in the lowest legal behavior disability quartile and 0.8 for those in the second lowest quartile as compared to those in the highest quartile. The odds are 0.7 for those with no illegal behaviors as compared to those with severe illegal behavior disability. As was expected, months of Medicaid eligibility is a highly significant predictor of observing a physical exam – each additional month of eligibility raises the odds ratio by approximately 1.3. This is not surprising, considering that the variable is a proxy for the length of the observation period. Dual eligibility is a highly significant predictor of having had the exam; this effect will be discussed more under Hypothesis 10. Being white as opposed to non-white raised the odds of having had a physical exam by a factor of approximately 1.3. Gender does not seem to be a consistently significant predictor. Age is generally marginally significant, with older recipients being more likely to receive the exam.

Table 38. Physical exam and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	1.26*** (1.14-1.40)
ADL Disability Quartile 2	1.42*** (1.28-1.57)
ADL Disability Quartile 3	1.27*** (1.15-1.41)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per months)	1.33*** (1.30-1.36)
Dual eligibility	1.63*** (1.49-1.78)
Age (per year)	1.004** (1.001-1.006)
Female	1.06 (0.99-1.14)
White	1.29*** (1.12-1.48)
Model 2: Physical Disability	
Physical Disability Quartile 1	1.49*** (1.36-1.64)
Physical Disability Quartile 2	1.35*** (1.23-1.49)
Physical Disability Quartile 3	1.17** (1.06-1.29)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.33*** (1.30-1.37)
Dual eligibility	1.57*** (1.44-1.72)
Age (per year)	1.004** (1.001-1.007)
Female	1.07 (0.99-1.14)
White	1.32*** (1.14-1.51)
Model 3: Communication Disability	
Communication Disability Quartile 1	1.06 (0.97-1.17)
Communication Disability Quartile 2	1.05 (0.95-1.16)
Communication Disability Quartile 3	0.97 (0.88-1.07)
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.33*** (1.30-1.37)
Dual eligibility	1.65*** (1.51-1.80)
Age (per year)	1.003* (1.000-1.006)
Female	1.05 (0.98-1.13)
White	1.25** (1.09-1.44)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	0.66*** (0.60-0.72)
Legal Behavior Disability Quartile 2	0.79*** (0.72-0.87)

Legal Behavior Disability Quartile 3	1.03 (0.93-1.14)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.32*** (1.29-1.35)
Dual eligibility	1.70*** (1.56-1.85)
Age (per year)	1.002 (0.999-1.005)
Female	1.08* (1.01-1.16)
White	1.30*** (1.13-1.49)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	0.67*** (0.60-0.74)
Illegal Behavior Disability - Mild	0.92 (0.82-1.04)
Illegal Behavior Disability - Moderate/Severe	reference category
Months of Medicaid eligibility (per month)	1.33*** (1.29-1.36)
Dual eligibility	1.68*** (1.54-1.83)
Age (per year)	1.003* (1.001-1.006)
Female	1.11** (1.04-1.19)
White	1.32*** (1.15-1.52)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	0.95 (0.85-1.05)
Cognitive Disability - Moderate	1.01 (0.91-1.13)
Cognitive Disability – Severe	1.09 (0.97-1.22)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.32*** (1.29-1.36)
Dual eligibility	1.68*** (1.54-1.84)
Age (per year)	1.001 (0.999-1.004)
Female	1.05 (0.98-1.13)
White	1.27** (1.10-1.46)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Dental cleaning

Table 39 presents the results of logistic regressions with dental cleaning as dependent variable. Rows 1 through 6 are models examining whether the probability of

having a dental cleaning in the last 12 months is affected by recipient's disability, controlling for months of Medicaid eligibility, age, gender, and race (dual eligibility is not an issue because Medicare does not cover dental services).

The largest effect in terms of odds ratios is again by the level of ADL disability. The odds of having had a dental cleaning in the previous 12 months are 1.8-1.9 times higher for a person in one of two least disabled quartiles than they are for a person in the most disabled quartile. Likewise, the odds of having the procedure are 1.6 for those in lowest physical disability quartile and 1.2-1.3 for those in second and third lowest disability quartiles as compared to the most physically disabled. Being in the most disabled communication disability quartile also lowers the odds of having had a dental cleaning – those in the two lower communication disability quartile are about 1.4-1.5 times as likely to have had the procedure than those in the highest quartile. Likewise, the most cognitively disabled recipients are least likely to have had a dental cleaning – the odds of having the procedure are about 1.3 for those with mild or moderate disability as compared to those with profound cognitive disability. Being most disabled in terms of both legal and illegal behavior disability again raises the probability of having had the service in the previous 12 months. The odds of having the procedure are 0.8 for those in the lower two legal behavior disability quartiles as compared to those in the highest quartile. The odds are 0.8 for those with no illegal behaviors as compared to those with severe illegal behavior disability. As expected, months of Medicaid eligibility are again highly significant. Age does not seem to predict the likelihood of receiving a dental cleaning in the last 12 months, and gender is only marginally significant, if at all. Race,

however, is highly statistically significant, with whites being more than twice as likely to have received the service than nonwhites.

Table 39. Dental cleaning and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	1.77*** (1.60-1.97)
ADL Disability Quartile 2	1.90*** (1.72-2.10)
ADL Disability Quartile 3	1.49*** (1.34-1.64)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.30*** (1.28-1.33)
Age (per year)	1.000 (0.997-1.002)
Female	1.09* (1.01-1.16)
White	2.22*** (1.94-2.54)
Model 2: Physical Disability	
Physical Disability Quartile 1	1.61*** (1.47-1.77)
Physical Disability Quartile 2	1.25*** (1.13-1.37)
Physical Disability Quartile 3	1.24*** (1.12-1.37)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.31*** (1.28-1.33)
Age (per year)	0.998 (0.996-1.001)
Female	1.09* (1.02-1.17)
White	2.21*** (1.93-2.53)
Model 3: Communication Disability	
Communication Disability Quartile 1	1.48*** (1.34-1.63)
Communication Disability Quartile 2	1.37*** (1.24-1.52)
Communication Disability Quartile 3	1.14* (1.03-1.25)
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.31*** (1.28-1.33)
Age (per year)	0.999 (0.997-1.002)
Female	1.07 (0.998-1.148)
White	2.19*** (1.91-2.51)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	0.78*** (0.71-0.86)
Legal Behavior Disability Quartile 2	0.84*** (0.77-0.93)

Legal Behavior Disability Quartile 3	1.08 (0.97-1.20)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.29*** (1.27-1.32)
Age (per year)	0.998* (0.995-1.000)
Female	1.10** (1.03-1.18)
White	2.20*** (1.93-2.52)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	0.83*** (0.74-0.93)
Illegal Behavior Disability - Mild	1.04 (0.92-1.18)
Illegal Behavior Disability - Moderate/Severe	reference category
Months of Medicaid eligibility	1.29*** (1.27-1.32)
Age (per year)	0.998 (0.996-1.001)
Female	1.11** (1.04-1.20)
White	2.19*** (1.92-2.51)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	1.26*** (1.14-1.40)
Cognitive Disability - Moderate	1.30*** (1.17-1.45)
Cognitive Disability – Severe	1.13* (1.01-1.28)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.30*** (1.28-1.33)
Age (per year)	0.998* (0.995-1.000)
Female	1.07 (1.00-1.15)
White	2.26*** (1.97-2.59)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Vision test

Table 40 presents the results of logistic regressions with vision test as dependent variable. Rows 1 through 6 are models examining whether the probability of having a vision test in the last 12 months is affected by recipient’s disability, controlling for months of Medicaid eligibility, dual eligibility status, age, gender, and race.

The largest effect in terms of odds ratios is once again by the level of ADL disability. The odds of having had a vision test in the previous 12 months are approximately 2.2 times higher for a person in one of two lower ADL disability quartiles than they are for a person in the highest quartile. The most cognitively disabled recipients are also least likely to have had a vision exam – the odds of having the procedure are about 1.9 for those with mild disability, 1.8 for those with moderate, and 1.5 for those with severe, as compared to people with profound cognitive disability. Those in the two lower communication disability quartiles are about 1.6-1.7 times as likely to have had the procedure than those in the highest quartile. The pattern is similar for physical disability – the odds of having the procedure are larger for those in lower disability quartiles (1.5 for least physically disabled, and 1.3 for those in the two middle quartiles) than they are for the most physically disabled. Being least disabled in terms of both legal and illegal behavior disability decreases the odds of having a vision exam by approximately 0.8 as compared to those with most behaviors. Months of Medicaid eligibility and dual eligibility status are both highly significant. Age is also a highly significant predictor, with older persons being more likely to have received a vision exam in the past 12 months. Gender is only marginally significant, if at all. Race is not a statistically significant predictor of receipt of vision test.

Table 40. Vision test and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	2.26*** (2.03-2.52)
ADL Disability Quartile 2	2.15*** (1.93-2.38)
ADL Disability Quartile 3	1.71*** (1.54-1.90)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.27*** (1.24-1.30)
Dual eligibility	1.50*** (1.37-1.64)
Age (per year)	1.017*** (1.014-1.019)
Female	1.08* (1.01-1.16)
White	1.07 (0.93-1.23)
Model 2: Physical Disability	
Physical Disability Quartile 1	1.52*** (1.38-1.67)
Physical Disability Quartile 2	1.35*** (1.22-1.49)
Physical Disability Quartile 3	1.30*** (1.18-1.44)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.23-1.29)
Dual eligibility	1.54*** (1.41-1.69)
Age (per year)	1.014*** (1.011-1.017)
Female	1.09* (1.02-1.17)
White	1.06 (0.92-1.22)
Model 3: Communication Disability	
Communication Disability Quartile 1	1.67*** (1.52-1.83)
Communication Disability Quartile 2	1.58*** (1.43-1.75)
Communication Disability Quartile 3	1.44*** (1.31-1.59)
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.27*** (1.24-1.29)
Dual eligibility	1.57*** (1.44-1.72)
Age (per year)	1.015*** (1.012-1.017)
Female	1.05 (0.98-1.13)
White	1.04 (0.90-1.19)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	0.85*** (0.77-0.93)
Legal Behavior Disability Quartile 2	0.93 (0.85-1.02)

Legal Behavior Disability Quartile 3	1.01 (0.91-1.12)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.25*** (1.22-1.28)
Dual eligibility	1.65*** (1.51-1.80)
Age (per year)	1.012*** (1.010-1.015)
Female	1.09* (1.02-1.17)
White	1.04 (0.90-1.19)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	0.84*** (0.75-0.93)
Illegal Behavior Disability - Mild	0.92 (0.81-1.03)
Illegal Behavior Disability - Moderate/Severe	reference category
Months of Medicaid eligibility (per month)	1.25*** (1.23-1.28)
Dual eligibility	1.65*** (1.51-1.78)
Age (per year)	1.013*** (1.010-1.015)
Female	1.10** (1.03-1.18)
White	1.05 (0.92-1.21)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	1.95*** (1.76-2.17)
Cognitive Disability - Moderate	1.78*** (1.59-1.99)
Cognitive Disability – Severe	1.48*** (1.31-1.67)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.27*** (1.24-1.30)
Dual eligibility	1.59*** (1.46-1.74)
Age (per year)	1.015*** (1.012-1.017)
Female	1.07 (1.00-1.15)
White	1.06 (0.92-1.23)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Hearing test

Table 41 presents the results of logistic regressions with hearing test as dependent variable. Rows 1 through 6 are models examining whether the probability of having a

hearing test in the last 12 months is affected by recipient’s disability, controlling for months of Medicaid eligibility, dual eligibility status, age, gender, and race.

The effect of various types of disability on the likelihood of having received a hearing exam is more difficult to describe. Physical disability does not have a statistically significant effect on the odds ratio. The odds of having the procedure are approximately 0.8 for those with least legal behaviors and no illegal behaviors as compared to people with more legal or any illegal behaviors. Being less disabled on the communication scale lowers the odds of having received a hearing test. This is not surprising considering that the communication disability scale contains an item about hearing problems. The pattern for ADL and cognitive disability is unusual. For both disabilities it appears that being in the next to highest disability quartile raises the odds of having had a hearing exam. Months of Medicaid eligibility is a highly significant predictor but dual eligibility only marginally so, if at all. Neither gender nor race appear to be predictive of receiving the procedure. Age is highly significant, with older people more likely to have received a hearing test.

Table 41. Hearing test and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	0.92 (0.80-1.06)
ADL Disability Quartile 2	1.17* (1.02-1.34)
ADL Disability Quartile 3	1.23** (1.08-1.41)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.21-1.31)
Dual eligibility	1.14* (1.01-1.29)
Age (per year)	1.016*** (1.013-1.020)
Female	0.98 (0.90-1.07)
White	0.95 (0.78-1.15)

Model 2: Physical Disability	
Physical Disability Quartile 1	1.07 (0.94-1.21)
Physical Disability Quartile 2	1.09 (0.96-1.24)
Physical Disability Quartile 3	1.10 (0.97-1.26)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.27*** (1.22-1.32)
Dual eligibility	1.11 (0.98-1.25)
Age (per year)	1.017*** (1.014-1.021)
Female	0.99 (0.90-1.08)
White	0.97 (0.80-1.18)
Model 3: Communication Disability	
Communication Disability Quartile 1	0.63*** (0.56-0.72)
Communication Disability Quartile 2	0.69*** (0.61-0.79)
Communication Disability Quartile 3	1.18** (1.05-1.33)
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.21-1.31)
Dual eligibility	1.17* (1.03-1.32)
Age (per year)	1.015*** (1.011-1.018)
Female	1.01 (0.92-1.11)
White	0.94 (0.77-1.13)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	0.81** (0.71-0.92)
Legal Behavior Disability Quartile 2	0.94 (0.83-1.06)
Legal Behavior Disability Quartile 3	1.04 (0.91-1.18)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.21-1.31)
Dual eligibility	1.12 (0.99-1.26)
Age (per year)	1.017*** (1.014-1.020)
Female	0.98 (0.90-1.08)
White	0.97 (0.80-1.18)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	0.80*** (0.69-0.92)
Illegal Behavior Disability - Mild	0.93 (0.80-1.09)
Illegal Behavior Disability - Moderate/Severe	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.21-1.32)
Dual eligibility	1.12 (0.99-1.26)

Age (per year)	1.018*** (1.014-1.021)
Female	1.00 (0.92-1.10)
White	0.99 (0.82-1.20)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	0.90 (0.79-1.04)
Cognitive Disability - Moderate	1.08 (0.94-1.24)
Cognitive Disability – Severe	1.26** (1.08-1.46)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.27*** (1.22-1.32)
Dual eligibility	1.16* (1.02-1.30)
Age (per year)	1.016*** (1.013-1.019)
Female	0.98 (0.89-1.07)
White	0.93 (0.76-1.13)

- * significant at 0.05 level
- ** significant at 0.01 level
- *** significant at 0.001 level

Influenza vaccine

Table 42 presents the results of logistic regressions with receiving influenza vaccine as dependent variable. Rows 1 through 6 are models examining whether the probability of having a flu vaccine in the last 12 months is affected by recipient’s disability, controlling for months of Medicaid eligibility, dual eligibility status, age, gender, and race.

All types of disability other than ADL disability have no effect on the odds of receiving the flu vaccine. Those in the highest ADL disability quartile are slightly less likely to have had the vaccine. Months of Medicaid eligibility and dual eligibility status are highly significant. Age is also highly statistically significant, with older recipients being more likely to have received the vaccine. Interestingly, both gender and race are significant, with females and whites having higher odds of having had the flu vaccine.

Table 42. Influenza vaccine and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	1.12 (0.99-1.26)
ADL Disability Quartile 2	1.36*** (1.22-1.53)
ADL Disability Quartile 3	1.21** (1.07-1.36)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.98*** (1.80-2.19)
Dual eligibility	1.60 *** (1.45-1.78)
Age (per year)	1.014*** (1.011-1.017)
Female	1.16*** (1.07-1.25)
White	1.42*** (1.19-1.70)
Model 2: Physical Disability	
Physical Disability Quartile 1	0.97 (0.88-1.08)
Physical Disability Quartile 2	1.05 (0.94-1.17)
Physical Disability Quartile 3	0.96 (0.86-1.07)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	2.00*** (1.81-2.20)
Dual eligibility	1.65*** (1.48-1.83)
Age (per year)	1.014*** (1.011-1.017)
Female	1.14** (1.06-1.23)
White	1.46*** (1.22-1.76)
Model 3: Communication Disability	
Communication Disability Quartile 1	0.97 (0.87-1.08)
Communication Disability Quartile 2	1.06 (0.95-1.19)
Communication Disability Quartile 3	1.07 (0.96-1.19)
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.98*** (1.80-2.18)
Dual eligibility	1.66*** (1.50-1.85)
Age (per year)	1.014*** (1.011-1.016)
Female	1.16*** (1.07-1.25)
White	1.45*** (1.21-1.73)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	0.99 (0.88-1.10)
Legal Behavior Disability Quartile 2	1.05 (0.95-1.17)

Legal Behavior Disability Quartile 3	1.10 (0.99-1.24)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	2.00*** (1.81-2.20)
Dual eligibility	1.62*** (1.46-1.80)
Age (per year)	1.014*** (1.011-1.016)
Female	1.16*** (1.07-1.25)
White	1.42*** (1.19-1.70)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	1.08 (0.95-1.22)
Illegal Behavior Disability - Mild	1.05 (0.92-1.21)
Illegal Behavior Disability - Moderate/Severe	reference category
Months of Medicaid eligibility (per month)	2.00*** (1.82-2.21)
Dual eligibility	1.63*** (1.47-1.81)
Age (per year)	1.014*** (1.011-1.016)
Female	1.15*** (1.06-1.24)
White	1.42*** (1.19-1.70)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	0.96 (0.86-1.08)
Cognitive Disability - Moderate	1.09 (0.96-1.23)
Cognitive Disability – Severe	1.09 (0.96-1.25)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.97*** (1.79-2.17)
Dual eligibility	1.64*** (1.48-1.83)
Age (per year)	1.013*** (1.010-1.016)
Female	1.16*** (1.07-1.25)
White	1.41*** (1.18-1.70)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Papanicolaou test

Table 43 presents the results of logistic regressions with pap smear as dependent variable. Only women 19 years of age and over at the time of their latest DD screening

assessment were included. Rows 1 through 6 are models examining whether the probability of having a pap smear in the last 12 months is affected by recipient's disability, controlling for months of Medicaid eligibility, dual eligibility status, age, and race.

The largest effect in terms of odds ratios is by the level of ADL disability. The odds of having had a pap smear in the previous 12 months are 3.2 times higher for a person in the lowest ADL disability quartile, 2.6 higher for a person in the second lowest quartile, and 1.4 higher for a person in the third lowest quartile than they are for a person in the most disabled quartile! The pattern is the same for communication disability – the odds of having the procedure are about 2.4 for those in lowest quartile, 2 for those in the second lowest quartile, and 1.4 for a person in the third lowest quartile as compared to those most disabled. Those with a mild cognitive disability are 2.4 times as likely to have had a pap smear than those with a profound cognitive disability, and those with a moderate cognitive disability 1.5 times as likely. Those most physically disabled are likewise least likely to have had the exam (odds are 2.2 for least physically disabled, 1.7 for those in second quartile, and 1.3 for those in third quartile). Having no illegal behaviors or being in the two quartiles with fewer legal behavior issues lessens the likelihood of having had the exam. Both months of Medicaid eligibility and dual eligibility status are statistically significant. Interestingly, age is a statistically significant negative predictor of the likelihood of having had a pap test – older recipients are less likely to have had the procedure. Race is marginally significant – surprisingly, white are less likely to have had the test than nonwhites.

Table 43. Pap test and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	3.21*** (2.57-4.00)
ADL Disability Quartile 2	2.61*** (2.10-3.25)
ADL Disability Quartile 3	1.41** (1.12-1.78)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.27*** (1.20-1.33)
Dual eligibility	1.17 (0.99-1.38)
Age (per year)	0.999 (0.998-1.001)
White	0.77* (0.60-0.98)
Model 2: Physical Disability	
Physical Disability Quartile 1	2.17*** (1.81-2.60)
Physical Disability Quartile 2	1.67*** (1.38-2.02)
Physical Disability Quartile 3	1.31** (1.07-1.61)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.24*** (1.18-1.31)
Dual eligibility	1.25** (1.06-1.47)
Age (per year)	0.993** (0.988-0.997)
White	0.77* (0.60-0.98)
Model 3: Communication Disability	
Communication Disability Quartile 1	2.42*** (2.01-2.92)
Communication Disability Quartile 2	2.00*** (1.64-2.45)
Communication Disability Quartile 3	1.41*** (1.14-1.74)
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.19-1.33)
Dual eligibility	1.27** (1.08-1.50)
Age (per year)	0.993** (0.989-0.998)
White	0.78* (0.61-0.99)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	0.78** (0.65-0.93)
Legal Behavior Disability Quartile 2	0.83* (0.70-0.99)
Legal Behavior Disability Quartile 3	1.03 (0.85-1.24)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.22*** (1.16-1.29)

Dual eligibility	1.41*** (1.20-1.66)
Age (per year)	0.989*** (0.985-0.994)
White	0.74* (0.58-0.94)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	0.61*** (0.49-0.75)
Illegal Behavior Disability - Mild	0.83 (0.66-1.05)
Illegal Behavior Disability - Moderate/Severe	reference category
Months of Medicaid eligibility (per month)	1.22*** (1.16-1.28)
Dual eligibility	1.39*** (1.18-1.64)
Age (per year)	0.991*** (0.986-0.996)
White	0.76* (0.60-0.97)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	2.38*** (1.92-2.94)
Cognitive Disability - Moderate	1.45*** (1.15-1.82)
Cognitive Disability – Severe	1.06 (0.81-1.38)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.20-1.33)
Dual eligibility	1.29** (1.09-1.53)
Age (per year)	0.993** (0.988-0.998)
White	0.76* (0.59-0.97)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Fecal occult blood test

Table 44 presents the results of logistic regressions with fecal occult blood test as dependent variable. Only recipients 51 and over years of age at the time of their latest DD screening assessment were included. Rows 1 through 6 are models examining whether the probability of having the test in the last 12 months is affected by recipient's disability, controlling for months of Medicaid eligibility, dual eligibility status, age, gender, and race.

There is no statistically significant relationship between any kind of disability and likelihood of receiving the test. This may be due to insufficient power resulting from the relatively small number of people in the sample for which the test is recommended. Months of Medicaid eligibility are once again highly significant, but dual eligibility status only marginally so. Neither age, nor gender, nor race are statistically significant predictors.

Table 44. Fecal occult blood test and disability

	Odds ratio (95% CI)
Model 1: ADL Disability	
ADL Disability Quartile 1	1.10 (0.77-1.58)
ADL Disability Quartile 2	1.20 (0.87-1.65)
ADL Disability Quartile 3	1.00 (0.73-1.37)
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.22*** (1.10-1.35)
Dual eligibility	2.16* (1.13-4.12)
Age (per year)	0.996 (0.983-1.008)
Female	1.23 (0.98-1.55)
Race	1.26 (0.54-2.92)
Model 2: Physical Disability	
Physical Disability Quartile 1	1.35 (0.99-1.86)
Physical Disability Quartile 2	1.00 (0.72-1.39)
Physical Disability Quartile 3	1.09 (0.79-1.51)
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.24*** (1.11-1.38)
Dual eligibility	2.16* (1.13-4.12)
Age (per year)	0.996 (0.983-1.009)
Female	1.26* (1.00-1.59)
Race	1.19 (0.51-2.77)
Model 3: Communication Disability	
Communication Disability Quartile 1	1.04 (0.57-1.43)
Communication Disability Quartile 2	0.84 (0.60-1.17)
Communication Disability Quartile 3	0.94 (0.69-1.27)

Communication Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.12-1.40)
Dual eligibility	2.16* (1.13-4.12)
Age (per year)	0.996 (0.984-1.009)
Female	1.23 (0.97-1.55)
Race	1.25 (0.54-2.91)
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	1.07 (0.76-1.51)
Legal Behavior Disability Quartile 2	0.99 (0.72-1.36)
Legal Behavior Disability Quartile 3	0.97 (0.69-1.37)
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility (per month)	1.23*** (1.11-1.36)
Dual eligibility	2.16* (1.13-4.12)
Age (per year)	0.995 (0.982-1.007)
Female	1.22 (0.97-1.54)
Race	1.23 (0.53-2.85)
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	0.85 (0.56-1.30)
Illegal Behavior Disability - Mild	0.71 (0.44-1.15)
Illegal Behavior Disability – Moderate/Severe	reference category
Months of Medicaid eligibility (per month)	1.22*** (1.10-1.35)
Dual eligibility	2.13* (1.12-4.08)
Age (per year)	0.994 (0.981-1.006)
Female	1.24 (0.98-1.56)
Race	1.23 (0.53-2.86)
Model 6: Cognitive Disability	
Cognitive Disability - Mild	0.92 (0.67-1.26)
Cognitive Disability - Moderate	1.00 (0.71-1.41)
Cognitive Disability – Severe	0.71 (0.49-1.03)
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility (per month)	1.22*** (1.10-1.35)
Dual eligibility	2.12* (1.11-4.04)
Age (per year)	0.995 (0.983-1.008)
Female	1.22 (0.97-1.54)
Race	1.25 (0.54-2.90)

* significant at 0.05 level

- ** significant at 0.01 level
- *** significant at 0.001 level

Summary of individual preventive procedures

Table 45 provides a summary of the effects of each type of disability on each type of recommended preventive procedure. The effects are shown only in terms of being positive or negative and their statistical significance. When there is no statistical significance, the effect is shown as zero.

While the effect of different types of disability on different preventive procedures is not uniform, a definite pattern emerges. This pattern can be summarized as follows. High levels of ADL disability, physical disability, communication disability, and cognitive disability tend to have a negative effect on the odds of receiving preventive procedures. This relationship is often non-linear (not shown in Table 45, but is evident from previous Tables 38-44), instead seeming to be of a “threshold” type - once a certain level of disability of recipient is observed, his/her odds of receiving recommended preventive procedure decreases (this is why quartiles were used instead of continuous disability scales). High levels of legal and illegal behavior disability, on the other hand, tend to have the opposite effect. Having the most legal and illegal behaviors often has a positive effect on the odds of receiving preventive procedures. This relationship seems to once again be non-linear. As expected, the months of Medicaid eligibility universally has a positive highly significant effect on the odds (due to it being the proxy for length of observation period). Dual eligibility status tends to have a positive effect on the odds of receiving recommended preventive care; this effect will be discussed more under

Hypothesis 10. With the exception of the pap test and possibly dental cleaning, age is positively related to the likelihood of having received recommended procedures. Gender is not a strong consistent predictor, but it does appear that females are somewhat more likely to receive certain procedures. The relationship of race to the likelihood is more complex. Whites are more likely to have received a dental cleaning, a flu vaccine, and a physical exam. Nonwhites seem to be more likely to have received a pap test. Race does not predict the receipt of a hearing test, a vision test, or a fecal occult blood test.

Table 45. Summary of individual preventive procedures and disability

	Dental cleaning	Flu vaccine	Vision test	Hearing test	Phys exam	Pap test	Fecal occult blood test
Model 1: ADL Disability							
ADL Disability Q1	+ ***	0	+ ***	0	+ ***	+***	0
ADL Disability Q2	+ ***	+ ***	+ ***	+ *	+ ***	+***	0
ADL Disability Q3	+ ***	+ **	+ ***	+ **	+ ***	+ **	0
ADL Disability Q4	ref	ref	ref	ref	ref	ref	ref
Mos of Medicaid eligibility	+ ***	+ ***	+ ***	+ ***	+ ***	+***	+ ***
Dual Eligibility	NA	+ ***	+ ***	+ *	+ ***	0	+ *
Age	0	+ ***	+ ***	+ ***	+ **	0	0
Female	+ *	+ ***	+ *	0	0	NA	0
White	+ ***	+ ***	0	0	+ ***	- *	0
Model 2: Physical Disability							
Physical Disability Q1	+ ***	0	+ ***	0	+ ***	+***	0
Physical Disability Q2	+ ***	0	+ ***	0	+ ***	+***	0
Physical Disability Q3	+ ***	0	+ ***	0	+ **	+ **	0
Physical Disability Q4	ref	ref	ref	ref	ref	ref	ref
Mos of Medicaid eligibility	+ ***	+ ***	+ ***	+ ***	+ ***	+***	+ ***
Dual Eligibility	NA	+ ***	+ ***	0	+ ***	+ **	+ *
Age	0	+ ***	+ ***	+ ***	+ **	- **	0
Female	+ *	+ **	+ *	0	0	NA	+ *
White	+ ***	+ ***	0	0	+ ***	- *	0
Model 3: Communication Disability							
Communication Disability Q1	+ ***	0	+ ***	- ***	0	+***	0
Communication Disability Q2	+ ***	0	+ ***	- ***	0	+***	0
Communication Disability Q3	+ *	0	+ ***	+ **	0	+***	0

Communication Disability Q4	ref	ref	ref	ref	ref	ref	ref
Mos of Medicaid eligibility	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***
Dual eligibility	NA	+ ***	+ ***	+ *	+ ***	+ **	+ *
Age	0	+ ***	+ ***	+ ***	+ *	- **	0
Female	0	+ ***	0	0	0	NA	0
White	+ ***	+ ***	0	0	+ **	- *	0
Model 4: Legal Behavior Disability							
Legal Behavior Disability Q1	- ***	0	- ***	- **	- ***	- **	0
Legal Behavior Disability Q2	- ***	0	0	0	- ***	- *	0
Legal Behavior Disability Q3	0	0	0	0	0	0	0
Legal Behavior Disability Q4	ref	ref	ref	ref	ref	ref	ref
Mos of Medicaid eligibility	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***
Dual eligibility	NA	+ ***	+ ***	0	+ ***	+ ***	+ *
Age	- *	+ ***	+ ***	+ ***	0	- ***	0
Female	+ **	+ ***	+ *	0	+ *	NA	0
White	+ ***	+ ***	0	0	+ ***	- *	0
Model 5: Illegal Behavior Disability							
Illegal Behavior Disab - None	- ***	0	- ***	- ***	- ***	- ***	0
Illegal Behavior Disab - Mild	0	0	0	0	0	0	0
Illegal Behavior Disab - Mod/Sev	ref	ref	ref	ref	ref	ref	ref
Mos of Medicaid eligibility	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***
Dual eligibility	NA	+ ***	+ ***	0	+ ***	+ ***	+ *
Age	0	+ ***	+ ***	+ ***	+ *	- ***	0
Female	+ **	+ ***	+ **	0	+ **	NA	0
White	+ ***	+ ***	0	0	+ ***	- *	0
Model 6: Cognitive Disability							
Cognitive Disability - Mild	+ ***	0	+ ***	0	0	+ ***	0
Cognitive Disability - Moderate	+ ***	0	+ ***	0	0	+ ***	0
Cognitive Disability – Severe	+ *	0	+ ***	+ **	0	0	0
Cognitive Disability – Profound	ref	ref	ref	ref	ref	ref	ref
Mos of Medicaid eligibility	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***	+ ***
Dual eligibility	NA	+ ***	+ ***	+ *	+ ***	+ **	+ *
Age	- *	+ ***	+ ***	+ ***	0	- **	0
Female	0	+ ***	0	0	0	NA	0
White	+ ***	+ ***	0	0	+ **	- *	0

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Preventive care – cumulative measure

The cumulative measure of preventive care was created by dividing the number of preventive procedures the person received by the number he/she was recommended to receive, thus signifying the proportion of recommended procedures received. The mean proportion of recommended procedures received was 0.35, with standard deviation of 0.25. This cumulative measure of preventive care can in effect be treated as a continuous variable due to the Central Limit Theorem.

Table 46 presents the results of linear regressions with cumulative preventive care as dependent variable. Rows 1 through 6 are models examining whether the proportion of recommended preventive procedures received is affected by recipient's disability, controlling for months of Medicaid eligibility, dual eligibility status, age, gender, and race.

The largest effect on the cumulative preventive care is the level of ADL disability. Being in the most disabled ADL disability quartile lowers the proportion of received recommended services by approximately .06-.09 as compared to those in the three less disabled ADL quartiles. Similarly, being in the most physically disabled quartile also lowers the proportion of received recommended services, although by not quite as much – by 0.03-0.06 percentage points. Having a profound cognitive disability lowers the proportion of received recommended services by about 0.03-0.04 as compared to those with a mild, moderate or a severe cognitive disability. Similarly, being in the most disabled communication disability quartile lowers the proportion by about 0.02-0.03 as compared to those in the less disabled communication disability quartiles. Both legal and

illegal behavior disabilities also have a significant effect on the proportion of recommended services received, but in different direction. Being most disabled in terms of legal behavior disability raises the proportion of received recommended services by about 0.05 as compared to those least disabled, and being most disabled in terms of illegal behavior disability raises the proportion by 0.04 as compared to those with no illegal behaviors. Both months of Medicaid eligibility and dual eligibility status are highly significant, with dual eligibility raising the proportion of recommended services received by approximately 9-10 percent. Age is not a significant predictor, but both gender and race are. Being white raised the proportion of procedures received by about 4-5 points. Being a woman lowers that proportion by 1-2 percent – a finding different from what the pattern of individual procedure results suggested.

Table 46. Cumulative measure of preventive care and disability

	Coefficient
Model 1: ADL Disability	
ADL Disability Quartile 1	0.071***
ADL Disability Quartile 2	0.088***
ADL Disability Quartile 3	0.059***
ADL Disability Quartile 4	reference category
Months of Medicaid eligibility	0.036***
Dual eligibility	0.092***
Age	0.000
Female	-.015***
White	0.047***
Model 2: Physical Disability	
Physical Disability Quartile 1	0.058***
Physical Disability Quartile 2	0.037***
Physical Disability Quartile 3	0.027***
Physical Disability Quartile 4	reference category
Months of Medicaid eligibility	0.037***

Dual eligibility	0.092***
Age	0.000
Female	-0.15***
White	0.049***
Model 3: Communication Disability	
Communication Disability Quartile 1	0.031***
Communication Disability Quartile 2	0.029***
Communication Disability Quartile 3	0.025***
Communication Disability Quartile 4	reference category
Months of Medicaid eligibility	0.037***
Dual eligibility	0.098***
Age	0.000
Female	-0.017***
White	0.044***
Model 4: Legal Behavior Disability	
Legal Behavior Disability Quartile 1	-0.045***
Legal Behavior Disability Quartile 2	-0.024***
Legal Behavior Disability Quartile 3	0.007
Legal Behavior Disability Quartile 4	reference category
Months of Medicaid eligibility	0.035***
Dual eligibility	0.102***
Age	0.000
Female	-0.013**
White	0.046***
Model 5: Illegal Behavior Disability	
Illegal Behavior Disability - None	-0.044***
Illegal Behavior Disability - Mild	-0.010
Illegal Behavior Disability – Moderate/Severe	reference category
Months of Medicaid eligibility	0.036***
Dual eligibility	0.101***
Age	0.000
Female	-0.010**
White	0.048***
Model 6: Cognitive Disability	
Cognitive Disability - Mild	0.033***
Cognitive Disability - Moderate	0.039***

Cognitive Disability – Severe	0.032***
Cognitive Disability – Profound	reference category
Months of Medicaid eligibility	0.037***
Dual eligibility	0.100***
Age	0.000
Female	-0.017***
White	0.046***

- * significant at 0.05 level
- ** significant at 0.01 level
- *** significant at 0.001 level

We considered the possibility that including pap smear, which is a relatively infrequently performed procedure, into the cumulative preventive care measure may distort the results by artificially (as it may be argued) inflating the proportion of procedures received for men. For sensitivity purposes, we re-calculated the cumulative measure, this time leaving pap smear out as one of qualifying recommended procedures. This created a common denominator for all people in our analysis. We then re-ran models 1-6. Relationships between disabilities and proportion of recommended procedures received are consistent with those in Table 46, but being female now consistently raises that proportion by between 0.01 and 0.02.

Hypothesis 8: Controlling for the level of disability, MR/DD adults living in own or family homes are least likely to receive recommended preventive medical care, whereas MR/DD adults living in ICF/MRs are most likely to receive preventive care, with foster/group homes falling somewhere in the middle.

Table 47 presents the proportion of individuals in each residential setting who had received the preventive services outlined above in the 12 months prior to their latest DD assessment (cases where the receipt of procedure could not be assigned were excluded). As is evident from the table, a larger proportion of residents of ICF/MRs and foster/group homes receive recommended preventive services than of residents of own homes and especially family homes. For example, 70% and 71% of residents of ICF/MRs and foster/group homes respectively received a dental cleaning, as compared to 52% of own home residents and only 38% of family home residents. Furthermore, ICF/MR and foster/group home residents received more total recommended procedures (proportion of 0.42 and 0.44 respectively) than those residing in their own homes (proportion of 0.29) and with families (proportion of 0.20).

Table 47. Proportion receiving individual preventive procedures by residence

	ICF/MR (n=2,271)	Foster/group home (n=6,998)	Family home (n=4,067)	Own home (n=1,254)	General population
Received physical exam	52.9% (n=2,268)	60.6% (n=6,983)	23.2% (n=3,910)	33.4% (n=1,194)	48% *
Received dental cleaning	69.7% (n=2,264)	70.8% (n=6,983)	37.8% (n=3,909)	52.3% (n=1,194)	72% ***
Received vision test	53.3% (n=2,268)	52.6% (n=6,983)	23.5% (n=3,910)	43.4% (n=1,194)	36% (among children) **
Received hearing test	28.0% (n=2,268)	20.4% (n=6,983)	4.2% (n=3,910)	8.1% (n=1,194)	
Received influenza vaccine	26.0% (n=2,268)	34.3% (n=6,983)	15.2% (n=3,910)	18.2% (n=1,194)	32% (ages 50-64) **
Received pap smear	16.6% (n=1,029)	22.8% (n=2,999)	11.4% (n=1,618)	22.9% (n=638)	53% *
Received fecal occult blood test	13.2% (n=778)	9.3% (n=1,891)	5.9% (n=372)	5.7% (n=262)	27% (any colon cancer screening) *
Proportion of recommended procedures received (mean/s.d.)	0.42 (0.23)	0.44 (0.23)	0.20 (0.21)	0.29 (0.24)	

* Source: The Commonwealth Fund 2001 Health Care Quality Survey

** Source: National Commission on Prevention Priorities, 2001

*** Source: CDC, 2008

Physical exam

Model 7 in Table 48 shows the effect place of residence has on probability of having had a physical exam in the previous 12 months, controlling only for months of Medicaid eligibility, dual eligibility status, age, gender, and race. Residents of foster/group homes are somewhat more likely to have had a physical exam than residents of ICF/MR. Those living with families are least likely to have received the service – odds of 0.3 as compared to ICF/MR residents. Those living in their own home are also less likely to have had the procedure – odds of 0.6 as compared to ICF/MR residents.

Finally, Model 8 incorporates all the disability domains in addition to other adjusters and place of residence. After controlling for disability, living in foster/group home lowered the odds of having received a physical exam in the previous 12 months to approximately 1.2 as compared to those living in an ICF/MR. The odds of having received the service for someone living in own home are 0.5 as compared to those living in an ICF/MR, after controlling for disability. The odds for those living in family home are approximately 0.3. Both months of Medicaid eligibility and dual eligibility status are highly significant, with dual eligibility raising the odds of receiving a physical exam. Age, gender, and race are also statistically significant, with older people, females, and whites being more likely to have received the exam.

Table 48. Physical exam and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	0.58*** (0.49-0.67)
Foster/group Home	1.25*** (1.13-1.38)
Family Home	0.31*** (0.27-0.35)

ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.23-1.30)
Dual eligibility	1.53*** (1.40-1.67)
Age (per year)	0.996** (0.994-0.999)
Female	1.11** (1.03-1.19)
White	1.15 (0.99-1.33)
Model 8: Disability and Residence	
Own Home	0.51*** (0.43-0.61)
Foster/group Home	1.19** (1.07-1.32)
Family Home	0.28*** (0.25-0.32)
ICF/MR	reference category
ADL Disability Quartile 1	1.42*** (1.22-1.67)
ADL Disability Quartile 2	1.51*** (1.31-1.74)
ADL Disability Quartile 3	1.28*** (1.13-1.44)
ADL Disability Quartile 4	reference
Physical Disability Quartile 1	1.38*** (1.23-1.55)
Physical Disability Quartile 2	1.24*** (1.11-1.39)
Physical Disability Quartile 3	1.07 (0.96-1.20)
Physical Disability Quartile 4	reference
Communication Disability Quartile 1	1.03 (0.90-1.17)
Communication Disability Quartile 2	0.99 (0.87-1.12)
Communication Disability Quartile 3	0.92 (0.82-1.04)
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	0.74*** (0.66-0.83)
Legal Behavior Disability Quartile 2	0.85** (0.77-0.95)
Legal Behavior Disability Quartile 3	1.06 (0.96-1.19)
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	0.78*** (0.68-0.88)
Illegal Behavior Disability - Mild	0.94 (0.83-1.07)
Illegal Behavior Disability – Moderate/Severe	reference
Cognitive Disability - Mild	0.65*** (0.56-0.76)
Cognitive Disability - Moderate	0.75*** (0.64-0.86)
Cognitive Disability – Severe	0.88 (0.77-1.01)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.32*** (1.29-1.35)

Dual eligibility	1.57*** (1.43-1.72)
Age (per year)	1.004** (1.001-1.007)
Female	1.11** (1.03-1.19)
White	1.31*** (1.13-1.51)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Dental cleaning

Model 7 in Table 49 shows the effect place of residence has on probability of having had a dental cleaning in the previous 12 months, controlling only for months of Medicaid eligibility, age, gender, and race. Residents of foster/group homes are slightly less likely to have had a dental cleaning as residents of ICF/MR, but that contrast is only marginally statistically significant. Those living with families are least likely to have received the service – odds of 0.2 as compared to ICF/MR residents. Those living in their own home are also less likely to have had the procedure – odds of 0.6 as compared to ICF/MR residents.

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. The patterns generally persist, but foster/group home residents become even less likely than ICF/MR residents to receive a dental cleaning (odds ratio of 0.8) and that contrast is now highly significant. The odds of receiving the service for someone living in own home are lowered to 0.4 as compared to those living in an ICF/MR. The odds for those living in family home remain approximately 0.2. Months of Medicaid eligibility are highly significant. Age, gender, and race are also statistically

significant, with younger people, females, and whites being more likely to have received the exam.

Table 49. Dental cleaning and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	0.64*** (0.54-0.74)
Foster/group Home	0.89* (0.80-0.99)
Family Home	0.24*** (0.21-0.27)
ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.26*** (1.24-1.29)
Age (per year)	0.987*** (0.985-0.990)
Female	1.12** (1.05-1.21)
White	2.01*** (1.75-2.32)
Model 8: Disability and Residence	
Own Home	0.42*** (0.35-0.50)
Foster/group Home	0.76*** (0.68-0.85)
Family Home	0.19*** (0.17-0.22)
ICF/MR	reference category
ADL Disability Quartile 1	1.75*** (1.47-2.07)
ADL Disability Quartile 2	1.75*** (1.51-2.03)
ADL Disability Quartile 3	1.37*** (1.20-1.55)
ADL Disability Quartile 4	reference
Physical Disability Quartile 1	1.16* (1.03-1.32)
Physical Disability Quartile 2	0.95 (0.84-1.07)
Physical Disability Quartile 3	1.00 (0.89-1.13)
Physical Disability Quartile 4	reference
Communication Disability Quartile 1	1.38*** (1.20-1.60)
Communication Disability Quartile 2	1.25*** (1.09-1.43)
Communication Disability Quartile 3	1.09 (0.96-1.24)
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	1.00 (0.88-1.13)
Legal Behavior Disability Quartile 2	0.96 (0.86-1.07)
Legal Behavior Disability Quartile 3	1.11 (0.97-1.25)
Legal Behavior Disability Quartile 4	reference

Illegal Behavior Disability - None	1.07 (0.93-1.22)
Illegal Behavior Disability - Mild	1.10 (0.96-1.26)
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	0.96 (0.82-1.13)
Cognitive Disability - Moderate	1.11 (0.95-1.30)
Cognitive Disability – Severe	1.04 (0.91-1.20)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.27*** (1.24-1.30)
Age (per year)	0.988*** (0.986-0.991)
Female	1.11** (1.03-1.19)
White	2.09*** (1.80-2.43)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Vision test

Model 7 in Table 50 shows the effect place of residence has on probability of having had a vision exam in the previous 12 months, controlling only for months of Medicaid eligibility, dual eligibility status, age, gender, and race. Residents of foster/group homes and own homes are no less likely to have had a vision test than residents of ICF/MRs. Those living with families are least likely to have received the service – odds of 0.4 as compared to ICF/MR residents.

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. After controlling for disability, a different pattern emerges. Living in foster/group home now lowered the odds of having received a vision exam in the previous 12 months to 0.7 and highly significant as compared to those living in an ICF/MR. The odds of receiving the service for someone living in own home are 0.6 as compared to those living in an ICF/MR and also highly statistically significant. The odds

for those living in family home are approximately 0.3. Months of Medicaid eligibility and dual eligibility status are highly significant, as is age, with older people being more likely to have received a vision test.

Table 50. Vision test and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	0.96 (0.82-1.11)
Foster/group Home	0.93 (0.84-1.02)
Family Home	0.35*** (0.32-0.40)
ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.24*** (1.21-1.26)
Dual eligibility	1.52*** (1.39-1.66)
Age (per year)	1.007*** (1.004-1.009)
Female	1.10** (1.02-1.18)
White	0.96 (0.84-1.11)
Model 8: Disability and Residence	
Own Home	0.59*** (0.49-0.70)
Foster/group Home	0.74*** (0.66-0.82)
Family Home	0.25*** (0.22-0.29)
ICF/MR	reference category
ADL Disability Quartile 1	1.92*** (1.63-2.26)
ADL Disability Quartile 2	1.78*** (1.53-2.06)
ADL Disability Quartile 3	1.47*** (1.30-1.67)
ADL Disability Quartile 4	reference
Physical Disability Quartile 1	1.03 (0.91-1.16)
Physical Disability Quartile 2	0.99 (0.88-1.11)
Physical Disability Quartile 3	1.01 (0.90-1.14)
Physical Disability Quartile 4	reference
Communication Disability Quartile 1	1.10 (0.96-1.26)
Communication Disability Quartile 2	1.13 (0.99-1.29)
Communication Disability Quartile 3	1.14* (1.01-1.28)
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	0.97 (0.86-1.09)

Legal Behavior Disability Quartile 2	0.99 (0.89-1.10)
Legal Behavior Disability Quartile 3	1.00 (0.90-1.12)
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	1.01 (0.86-1.14)
Illegal Behavior Disability - Mild	0.96 (0.84-1.09)
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	1.55*** (1.32-1.81)
Cognitive Disability - Moderate	1.49*** (1.28-1.73)
Cognitive Disability – Severe	1.31*** (1.14-1.51)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.24*** (1.22-1.28)
Dual eligibility	1.39*** (1.27-1.53)
Age (per year)	1.010*** (1.007-1.013)
Female	1.09* (1.01-1.17)
White	0.98 (0.84-1.14)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Hearing test

Model 7 in Table 51 shows the effect place of residence has on probability of having had a hearing exam in the previous 12 months, controlling only for months of Medicaid eligibility, dual eligibility status, age, gender, and race. Residents of foster/group homes are less likely to have had a hearing test than residents of ICF/MR (odds ratio of 0.6). Those living with families are least likely to have received the service – odds ratio of 0.1 as compared to ICF/MR residents. Those living in their own home are also less likely to have had the procedure, with odds ratio of approximately 0.3.

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. After controlling for disability, the same pattern remains, with the

odds ratios approximately the same. Months of Medicaid eligibility are highly significant, but dual eligibility status is not. Age is also highly significant, with older recipients being more likely to have had a hearing exam. Gender and race are not significant.

Table 51. Hearing test and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	0.28*** (0.22-0.36)
Foster/group Home	0.64*** (0.57-0.71)
Family Home	0.13*** (0.11-0.16)
ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.21*** (1.16-1.26)
Dual eligibility	1.01(0.89-1.14)
Age (per year)	1.010*** (1.006-1.013)
Female	1.01 (0.92-1.10)
White	0.84 (0.69-1.02)
Model 8: Disability and Residence	
Own Home	0.24*** (0.18-0.31)
Foster/group Home	0.60*** (0.54-0.68)
Family Home	0.12*** (0.09-0.14)
ICF/MR	reference category
ADL Disability Quartile 1	1.33** (1.07-1.65)
ADL Disability Quartile 2	1.32** (1.10-1.59)
ADL Disability Quartile 3	1.19* (1.01-1.39)
ADL Disability Quartile 4	reference
Physical Disability Quartile 1	1.15 (0.98-1.34)
Physical Disability Quartile 2	1.13 (0.97-1.32)
Physical Disability Quartile 3	1.10 (0.95-1.28)
Physical Disability Quartile 4	reference
Communication Disability Quartile 1	0.52*** (0.43-0.62)
Communication Disability Quartile 2	0.57*** (0.48-0.68)
Communication Disability Quartile 3	1.05 (0.91-1.22)

Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	1.22* (1.05-1.43)
Legal Behavior Disability Quartile 2	1.19* (1.04-1.37)
Legal Behavior Disability Quartile 3	1.14 (0.99-1.31)
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	0.91 (0.78-1.08)
Illegal Behavior Disability - Mild	0.92 (0.77-1.08)
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	1.65*** (1.35-2.01)
Cognitive Disability - Moderate	1.59*** (1.32-1.92)
Cognitive Disability – Severe	1.47*** (1.23-1.74)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.21*** (1.16-1.26)
Dual eligibility	0.98 (0.87-1.12)
Age (per year)	1.008*** (1.005-1.012)
Female	1.06 (0.96-1.16)
White	0.84 (0.68-1.03)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Influenza vaccine

Model 7 in Table 52 shows the effect place of residence has on probability of having had a flu vaccine in the previous 12 months, controlling only for months of Medicaid eligibility, dual eligibility status, age, gender, and race. Surprisingly, residents of foster/group homes are more likely to have had a flu vaccine than residents of ICF/MR (odds ratio of 1.5). Those living with families are less likely to have received the service – odds ratio of 0.8 as compared to ICF/MR residents. Those living in their own home are about as likely to have had the procedure as ICF/MR residents.

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. After controlling for disability, the same pattern remains, with the odds ratios approximately the same. Both months of Medicaid eligibility and dual eligibility status are highly significant, with dually eligible recipients being more likely to have received a flu vaccine. Age, gender, and race are also highly statistically significant. Older recipients, females, and whites are more likely to have received the vaccine.

Table 52. Influenza vaccine and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	0.97 (0.80-1.16)
Foster/group Home	1.45*** (1.30-1.62)
Family Home	0.77*** (0.67-0.89)
ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.89*** (1.72-2.08)
Dual eligibility	1.53*** (1.38-1.70)
Age (per year)	1.013*** (1.010-1.017)
Female	1.18*** (1.09-1.28)
White	1.36** (1.13-1.63)
Model 8: Disability and Residence	
Own Home	1.05 (0.85-1.29)
Foster/group Home	1.46*** (1.30-1.64)
Family Home	0.76*** (0.65-0.88)
ICF/MR	reference category
ADL Disability Quartile 1	1.31** (1.09-1.57)
ADL Disability Quartile 2	1.50*** (1.28-1.76)
ADL Disability Quartile 3	1.25** (1.09-1.44)
ADL Disability Quartile 4	reference
Physical Disability Quartile 1	0.85* (0.75-0.97)
Physical Disability Quartile 2	0.93 (0.82-1.06)
Physical Disability Quartile 3	0.87* (0.77-0.99)

Physical Disability Quartile 4	reference
Communication Disability Quartile 1	0.96 (0.82-1.11)
Communication Disability Quartile 2	1.01 (0.87-1.16)
Communication Disability Quartile 3	1.04 (0.91-1.18)
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	1.07 (0.94-1.22)
Legal Behavior Disability Quartile 2	1.07 (0.95-1.20)
Legal Behavior Disability Quartile 3	1.11 (0.98-1.25)
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	1.13 (0.98-1.31)
Illegal Behavior Disability - Mild	1.05 (0.90-1.22)
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	0.88 (0.74-1.04)
Cognitive Disability - Moderate	0.97 (0.82-1.14)
Cognitive Disability – Severe	1.02 (0.88-1.19)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.85*** (1.69-2.03)
Dual eligibility	1.58*** (1.42-1.76)
Age (per year)	1.013*** (1.010-1.016)
Female	1.17*** (1.08-1.27)
White	1.28*** (1.14-1.67)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Papanicolaou test

Model 7 in Table 53 shows the effect place of residence has on probability of having had a pap smear in the previous 12 months, controlling only for months of Medicaid eligibility, dual eligibility status, age, and race. Surprisingly, residents of own homes and foster/group homes are more likely to have had a pap smear than residents of

ICF/MR (odds ratio of 1.7 and 1.3 respectively). Those living with families are less likely to have received the service – odds ration of 0.6 as compared to ICF/MR residents.

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. After controlling for disability, a different pattern emerges. When disability is controlled for, those living in foster/group homes or in their own homes were as likely to have received a pap smear as residents of ICF/MRs. Living with family lowered the odds further to 0.5 as compared to living in ICF/MR. Months of Medicaid eligibility are significant, whereas dual eligibility status is not. Age is not significant either, and race only marginally so, with whites being less likely to have received a pap test than nonwhites.

Table 53. Pap test and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	1.74*** (1.34-2.26)
Foster/group Home	1.31** (1.09-1.59)
Family Home	0.60** (0.47-0.76)
ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.23*** (1.16-1.29)
Dual eligibility	1.29** (1.09-1.52)
Age (per year)	0.988*** (0.983-0.993)
White	0.71** (0.56-0.90)
Model 8: Disability and Residence	
Own Home	0.97 (0.72-1.30)
Foster/group Home	1.00 (0.82-1.23)
Family Home	0.48*** (0.37-0.63)
ICF/MR	reference category
ADL Disability Quartile 1	2.23*** (1.60-3.10)
ADL Disability Quartile 2	1.94*** (1.44-2.63)
ADL Disability Quartile 3	1.24 (0.94-1.63)

ADL Disability Quartile 4	reference
Physical Disability Quartile 1	1.15 (0.91-1.44)
Physical Disability Quartile 2	1.00 (0.80-1.26)
Physical Disability Quartile 3	0.92 (0.73-1.15)
Physical Disability Quartile 4	reference
Communication Disability Quartile 1	1.28 (0.97-1.69)
Communication Disability Quartile 2	1.31 (1.00-1.71)
Communication Disability Quartile 3	1.10 (0.85-1.42)
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	0.81 (0.65-1.01)
Legal Behavior Disability Quartile 2	0.83 (0.68-1.01)
Legal Behavior Disability Quartile 3	1.01 (0.82-1.24)
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	0.72** (0.56-0.92)
Illegal Behavior Disability - Mild	0.86 (0.67-1.11)
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	1.21 (0.88-1.67)
Cognitive Disability - Moderate	0.87 (0.64-1.20)
Cognitive Disability – Severe	0.82 (0.60-1.10)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.27*** (1.20-1.35)
Dual eligibility	1.06 (0.89-1.26)
Age (per year)	0.996 (0.990-1.001)
White	0.77* (0.60-0.99)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Fecal occult blood test

Model 7 in Table 54 shows the effect place of residence has on probability of having had the test in the previous 12 months, controlling only for months of Medicaid eligibility, dual eligibility status, age, gender, and race. People living in family home or in own homes are least likely to have had the test (odds ratio of 0.4 and 0.5 respectively

as compared to ICF/MR residents), followed by foster/group home residents (odds ratio of 0.6 as compared to ICF/MR residents).

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. After controlling for disability, the same pattern remains, with the odds ratios approximately the same (except for family home residents, for whom the odds ratio was further reduced to 0.3 as compared to ICF/MR residents). Months of Medicaid eligibility are highly significant, whereas dual eligibility status is only marginally so, with dually eligible recipients having a greater likelihood of receiving the test. Age, gender, and race are not statistically significant predictors.

Table 54. Fecal occult blood test and residence

	Odds ratio (95% CI)
Model 7: Residence	
Own Home	0.48** (0.27-0.84)
Foster/group Home	0.64*** (0.49-0.83)
Family Home	0.43*** (0.26-0.69)
ICF/MR	reference category
Months of Medicaid eligibility (per month)	1.20*** (1.09-1.33)
Dual eligibility	2.19* (1.15-4.20)
Age (per year)	0.998 (0.985-1.011)
Female	1.22 (0.97-1.53)
White	1.15 (0.49-2.68)
Model 8: Disability and Residence	
Own Home	0.37**(0.20-0.70)
Foster/group Home	0.58*** (0.44-0.77)
Family Home	0.32*** (0.19-0.55)
ICF/MR	reference category
ADL Disability Quartile 1	1.19 (0.71-1.99)
ADL Disability Quartile 2	1.21 (0.78-1.88)
ADL Disability Quartile 3	1.00 (0.69-1.45)
ADL Disability Quartile 4	reference

Physical Disability Quartile 1	1.34 (0.91-1.98)
Physical Disability Quartile 2	0.98 (0.67-1.43)
Physical Disability Quartile 3	1.02 (0.72-1.46)
Physical Disability Quartile 4	reference
Communication Disability Quartile 1	1.07 (0.70-1.65)
Communication Disability Quartile 2	0.91 (0.61-1.38)
Communication Disability Quartile 3	1.00 (0.70-1.44)
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	1.25 (0.84-1.84)
Legal Behavior Disability Quartile 2	1.04 (0.73-1.47)
Legal Behavior Disability Quartile 3	0.95 (0.65-1.37)
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	0.90 (0.57-1.44)
Illegal Behavior Disability - Mild	0.74 (0.45-1.21)
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	0.93 (0.60-1.45)
Cognitive Disability - Moderate	0.87 (0.56-1.34)
Cognitive Disability – Severe	0.71 (0.47-1.07)
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	1.26*** (1.11-1.42)
Dual eligibility	2.16* (1.13-4.15)
Age (per year)	1.000 (0.986-1.014)
Female	1.26 (0.99-1.61)
White	1.03 (0.44-2.43)

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Summary of individual preventive procedures

Table 55 provides a summary of the effect of residence on each type of recommended preventive procedure. The effects are from Model 8 and are shown only in terms of being positive or negative and their statistical significance. When there is no statistical significance, the effect is shown as zero. Other adjustors are not included in

the summary table for the sake of brevity – please refer to tables L through R for estimates of adjustor effects.

There are several important general conclusions that can be drawn from the summary table. The first is that MR/DD people living in community-based residential options of foster/group homes, family homes, and own homes are generally less likely to receive recommended preventive health care than those living in ICF/MRs, even when disability is not controlled for (Models 7). There are exceptions, such as with pap smear, where residents of own homes and foster/group homes are more likely to receive the procedure, or flu vaccine, where residents of foster/group home more likely to have gotten the vaccine than residents of ICF/MRs. However, when disability is controlled for, the effect of residence becomes even more uniform and unequivocal (Model 8). For all preventive services other than flu vaccine and physical exam, residents of community-based residential options are less likely (or as likely as, in the case of pap smear and flu vaccine) than residents of ICF/MRs to have received the recommended procedures. Importantly, if ICF/MR residents appeared more likely to have received care in Model 7, controlling for their disability in all cases amplified the gap in likelihood between ICF/MRs and other residential options. If, on the other hand, ICF/MR residents appeared less likely to have received care, controlling for disability closed the gap. For example, before controlling for disability, residents of foster/group homes were slightly more likely to have received a dental cleaning as residents of ICF/MRs. After controlling for disability, however, residents of foster/group homes are seen to be less likely to have had the cleaning than ICF/MR residents. In case of two procedures (flu vaccine and physical

exam), residents of foster/group homes were more likely to have received them than residents of ICF/MRs even after controlling for disability.

Furthermore, as is evident from Tables 48-54, recipients living with families are universally least likely to receive preventive procedures. Residents of their own homes do somewhat better, and residents of foster/group homes come closest to ICF/MR residents in terms of their receipt of preventive health care.

Table 55. Summary of individual preventive procedures and residence

	Dental cleaning	Flu vaccine	Vision test	Hearing test	Physical exam	Pap test	Fecal occult blood test
Model 7: Residence							
Own Home	- ***	0	0	- ***	- ***	+ ***	- **
Foster/group Home	- *	+ ***	0	- ***	+ ***	+ **	- ***
Family Home	- ***	- ***	- ***	- ***	- ***	- **	- ***
ICF/MR	reference	reference	reference	reference	reference	reference	reference
Model 8: Disability and Residence							
Own Home	- ***	0	- ***	- ***	- ***	0	- **
Foster/group Home	- ***	+ ***	- ***	- ***	+ **	0	- ***
Family Home	- ***	- ***	- ***	- ***	- ***	- ***	- ***
ICF/MR	reference	reference	reference	reference	reference	reference	reference

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Not shown in Table 55 are the patterns for the adjustors. As evident from Tables 48-54, however, dual eligibility generally raises the likelihood of receiving preventive procedures (with the exception of hearing test and perhaps pap test). This effect will be discussed more under Hypothesis 10. As expected, months of Medicaid eligibility universally have a positive and highly significant effect on the odds (due to it being the proxy for length of observation period). Gender is also significant, with females being more likely to receive most procedures (other than hearing exam and fecal occult blood

test). Being white is associated with higher likelihood of receiving a physical exam, a dental cleaning, and a flu vaccine, but with lower odds of receiving a pap test. Being older raises the likelihood of getting a physical exam, a vision or hearing test, and a flu vaccine, but lowers the odds of getting a dental cleaning and perhaps a pap test. Higher levels of ADL, physical, communication, and cognitive disabilities are associated with decreased likelihood of receiving most procedures, with the relationship appearing to be non-linear (possible threshold effect). Being most disabled in terms of both legal and illegal behavior disabilities, on the other hand, actually raises the odds.

Preventive care – cumulative measure

Model 7 in Table 56 shows the effect place of residence has on the proportion of recommended services received, controlling only for months of Medicaid eligibility, dual eligibility status, age, gender, and race. Living in family home lowers the proportion of recommended services received by 0.20 as compared to living in an ICF/MR, whereas living in own home lowers the proportion by 0.08. Foster/group home residents appear to receive approximately the same proportion of services as ICF/MR residents.

Model 8 incorporates all the disability domains in addition to other adjustors and place of residence. After controlling for disability, the same pattern remains for family home and own home residents, but the effect of residence is even more pronounced. Family home lowers the proportion of received recommended services by 0.23 as compared to ICF/MR and own home lowers it by 0.12. In addition, after controlling for disability there is a statistically significant difference between ICF/MR residents and

foster/group home residents. Living in a foster/group home lowers the proportion of received services by 0.02 as compared to living in ICF/MR. Both months of Medicaid eligibility and dual eligibility status are highly significant, with dual eligibility raising the proportion of services received by approximately 7-8 percentage points. Being white raised the proportion by 0.03, being a female lowers the proportion slightly by 0.01, and being older is associated with fewer services received. In addition, high ADL and cognitive disabilities also lower the proportion of services received.

Table 56. Cumulative measure of preventive care and residence

	Coefficient
Model 7: Residence	
Own Home	-0.081***
Foster/group Home	0.005
Family Home	-0.201***
ICF/MR	reference category
Months of Medicaid eligibility (per month)	0.029***
Dual eligibility	0.082***
Age (per year)	-0.001***
Female	-0.011**
White	0.028***
Model 8: Disability and Residence	
Own Home	-0.123***
Foster/group Home	-0.015**
Family Home	-0.227***
ICF/MR	reference
ADL Disability Quartile 1	0.077***
ADL Disability Quartile 2	0.078***
ADL Disability Quartile 3	0.045***
ADL Disability Quartile 4	reference
Physical Disability Quartile 1	0.020***
Physical Disability Quartile 2	0.007
Physical Disability Quartile 3	0.001

Physical Disability Quartile 4	reference
Communication Disability Quartile 1	0.002
Communication Disability Quartile 2	0.002
Communication Disability Quartile 3	0.010
Communication Disability Quartile 4	reference
Legal Behavior Disability Quartile 1	0.002
Legal Behavior Disability Quartile 2	0.001
Legal Behavior Disability Quartile 3	0.015**
Legal Behavior Disability Quartile 4	reference
Illegal Behavior Disability - None	-0.006
Illegal Behavior Disability - Mild	-0.002
Illegal Behavior Disability - Moderate/Severe	reference
Cognitive Disability - Mild	0.020*
Cognitive Disability - Moderate	0.027***
Cognitive Disability – Severe	0.022**
Cognitive Disability – Profound	reference
Months of Medicaid eligibility (per month)	0.030***
Dual eligibility	0.070***
Age (per year)	-0.001***
Female	-0.011**
White	0.031***

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

Again we considered the possibility that including pap smear may distort the results. As with models 1 through 6, we re-ran models 7 and 8 with a re-calculated cumulative measure which left pap smear out of both the numerator and the denominator. None of the relationships in Table 56 were affected to any significant degree, except for gender. Being female actually raises the new proportion by approximately 0.02.

Hypothesis 9: Controlling for other factors, MR/DD adults in CDCS are more likely to receive recommended preventive medical than those not in either SILS or CDCS program.

The formal investigation of this hypothesis had to be abandoned because of insufficient power.

Research question 2: How does receipt of preventive care vary across MR/DD adults with dual coverage (Medicare and Medicaid) and Medicaid-only coverage?

Hypothesis 10: Controlling for other factors such as disability and place of residence, MR/DD adults with dual coverage are more likely to receive preventive care than those with Medicaid-only coverage.

In almost all of the previous analyses the control variable of dual eligibility was highly statistically significant and had a positive effect on the likelihood of receiving recommended preventive care. However, some additional considerations need to be taken into account before the effect of dual eligibility can be interpreted directly.

In order to estimate the effect that dual eligibility has on the likelihood of receiving preventive health care procedures, it is necessary to control for any private insurance. Medicaid is the insurance of last resort, so any other insurance plans, including Medicare or private insurance, have to pay before Medicaid will pay. Because our utilization data includes only Medicaid and Medicare files, any procedure paid for by private insurance plans will not be captured in our analysis. For example, if a person has private insurance in addition to Medicaid, and receives a physical exam, which is covered by the private plan, that physical exam will not show up in our data. On the other hand, if a person has Medicare in addition to Medicaid and receives a physical exam, that physical exam will show up in our Medicare data. It will then look from our available data as if being dually eligible makes one more likely to receive a physical exam.

Controlling for private insurance will be done by including the number of months the recipient had private insurance during the observation period as an adjustor. The MAX Personal Summary Record was used to calculate the number of months each person had private insurance in the 12 months of their look-back.

Furthermore, to be absolutely certain that a person had Medicaid coverage during the same time that she/he had Medicare coverage, we will exclude cases where a person was not eligible for Medicaid for all 12 months of her/his observation period. This exclusion criterion leaves 13,038 cases for analysis.

Table 57 presents a summary of the effect of dual eligibility on the likelihood of receiving each type of recommended preventive procedure, controlling for disability, residence, the number of private insurance months, age, gender, and race. Only the effect (odds ratio) of dual eligibility is shown in the table.

For at least some preventive procedures, dual eligibility affects the likelihood of receipt. For example, it raises the odds ratio of having received a flu vaccine by 1.45, the odds of having had a vision test by 1.3, and the odds of having had a physical exam by 1.2. For other preventive procedures, dual eligibility is either not statistically significant, or is only marginally so. When the proportion of recommended preventive procedures received (cumulative measure) is taken as the dependent variable, dual eligibility status is highly statistically significant and raises the proportion of procedures received by 0.055.

Table 57. Preventive health care and dual eligibility

	Flu vaccine (odds ratio/ 95% CI)	Vision test (odds ratio/ 95% CI)	Hearing test (odds ratio/ 95% CI)	Physical exam (odds ratio/ 95% CI)	Pap test (odds ratio/ 95% CI)	Fecal occult blood test (odds ratio/ 95% CI)	Cumulative preventive care measure (coefficient)
Dual eligibility	1.45*** (1.30-1.62)	1.30*** (1.17-1.43)	0.94 (0.82-1.07)	1.24*** (1.12-1.38)	1.05 (0.88-1.26)	2.03* (1.05-3.90)	0.055***

* significant at 0.05 level

** significant at 0.01 level

*** significant at 0.001 level

VII. Discussion

We confirmed our hypotheses of a negative relationship between the level of disability and likelihood of receiving recommended preventive care for mentally retarded/developmentally disabled adults. Our analyses provide support for the theory that the level of disability of a patient with mental retardation/developmental disabilities may affect the likelihood of that patient receiving recommended preventive health care. With the exception of behavior disability, the most disabled individuals are least likely to receive preventive health care. Specifically, high levels of ADL disability, physical disability, communication disability, and cognitive disability have a negative effect on receipt of preventive care. An interesting and somewhat unexpected finding is that those with the most behaviors, both legal and illegal, tend to be more likely to receive recommended preventive care (at least in terms of certain individual procedures). A likely explanation is that this is due to recipients with most behaviors also having the most monitoring and oversight. The cumulative measure of preventive care, despite its shortcoming of assuming equal weights for all preventive procedures, provides further support for the negative impact of high levels of ADL, physical, communication, and cognitive disabilities.

These findings, while expected, raise some concerns. There is no intrinsic reason why having a higher level of disability should decrease a developmentally disabled person's chances of getting preventive medical services. This discrepancy may be due to conscious or subconscious value judgments on behalf of caretakers, who feel that it's not worth it to secure these services for the most developmentally disabled. It may also be

due to access barriers – it is probably harder to find a doctor qualified and willing to treat someone who is profoundly cognitively disabled, for example, or to get someone with a very high level of physical disability to an appointment.

We also confirmed our hypotheses on the importance of where a person with MR/DD lives to his/her receiving preventive care. Our analysis provides support for the theory that the place of residence of a person with mental retardation/developmental disabilities has an effect on the likelihood of that person receiving recommended preventive health care, even after controlling for disability. As was demonstrated before, there are differences in disability levels across the different types of residence. It was also shown that there is a relationship between disability levels and receipt of preventive care. It was thus very important to take disability into account when investigating the effect of residence on receipt of preventive care. In fact, controlling for disability in many cases amplifies the effect of residence. Failure to take disability into account may actually mask the magnitude of difference in likelihood between ICF/MR residents and community-based residents, or may lead one to incorrectly conclude in some cases that community-based residents are as likely or even more likely than ICF/MR residents to receive some preventive health care services. Controlling for disability has the effect of magnifying the importance of place of residence. People living with their families are least likely to receive preventive care, followed by people living in their own homes. The difference in the likelihood of receipt of preventive care is particularly striking between those living in ICF/MRs and those living with families. Only foster/group home residents came close to receiving the level of preventive care that is received by residents

of ICF/MRs, in some cases even exceeding it. It is important to remember, however, that we were unable to distinguish between small ICF/MRs with four residents and foster/group homes in our analyses.

Existing research up to this point has largely been descriptive or utilized small convenience samples and did not attempt to consider differences in disability. Our study was able to improve on prior research by utilizing a large sample and being able to control for various types of disability of recipients.

The findings that living in community settings may decrease the likelihood of receiving preventive health care services raise concerns. If the level of medical care provided at institutions such as ICF/MRs is taken to be the gold standard, then the level of preventive care received by people living in community-based settings is inadequate. Community-based care is currently the predominant service mode for individuals with developmental disabilities. It is generally viewed as being preferable in that it improves quality of life and many other outcomes. However, since health services available to people with MR/DD have not advanced at the same pace as residential community-based services, the autonomy associated with community-based placement leads to more barriers to receiving health care. The freedom comes with a price, in the form of decreased access to preventive medical services. Health care providers in many countries have raised concerns about compromised health care quality for individuals with MR/DD living in the community (Krahn, Hammond, Turner, 2006).

We also found that dually eligible individuals who are covered by Medicare in addition to Medicaid are more likely to receive preventive health care, controlling for

disability, age, and other factors. While this finding is not surprising, it is disconcerting. People with MR/DD experience difficulties accessing preventive health. The reasons are manifold and varied, but having Medicaid as their only insurance plan seems to add to those barriers. If, in addition to Medicaid, the person is covered by Medicare, Medicare becomes the primary insurance for health care services. Medicare's reimbursement rates for medical procedures are higher than Medicaid's and more physicians may be willing to treat Medicare patients. Thus, a dually eligible person may experience fewer barriers in accessing recommended preventive care. Many patients with mental retardation/developmental disabilities may experience difficulty in finding a medical provider willing or able to treat someone with MR/DD. In addition, however, Medicaid's low reimbursement rates may make it even more difficult for MR/DD adults to access recommended preventive services due to unwillingness of many physicians to treat Medicaid patients in general. Changing re-imbursement policies for MR/DD individuals receiving Medicaid may help alleviate the problem.

It is important to re-iterate once more, however, that good and consistent data on the effectiveness of preventive care in reducing morbidity and/or mortality is surprisingly sparse, even for the general population, but especially so for the developmentally disabled population. Most of the recommendations and guidelines are based on nothing more than expert medical opinion, not evidence-based research. It is possible then, that the highest level of receipt of preventive health care constitutes a waste of resources. Lower levels of preventive health care services received by residents of family homes and own homes may constitute rational under-use. ICF/MRs and group homes could

have less leeway for that rational under-use due to the higher amount of oversight and necessity to adhere to prescribed practices. This is an area where further research is needed. Those recipients living in family homes, for example, and receiving the least amount of preventive services may have health outcomes as good as those recipients living in ICF/MRs. This type of finding may provide evidence for the overuse of preventive services in ICF/MRs and group homes.

If it is believed that the recommended preventive health care services are essential, then steps need to be taken to increase compliance. Reasons for why people with MR/DD living with families or in their own homes are less likely to receive recommended preventive services need to be investigated. There may be access barriers, such as transportation or waiting lists, or shortage of medical providers willing to treat patients with MR/DD. There may be information barriers, such as lack of information about which procedures are recommended and how often, or which doctors are willing to treat and knowledgeable about people with MR/DD. There may be covert or overt value judgments on the part of family members about who should and shouldn't receive certain preventive services. As mentioned above, there may be implicit judgments that some preventive services for certain people are not needed or even harmful. These judgments may or may not be justified.

As in many observational studies, there also exists a potential for selection bias. People with MR/DD living with families or in their own home may be fundamentally different in some way from those living in group homes or ICF/MRs. If this difference affects their receipt of preventive care and is not measured, we may mistakenly attribute

observed differences in likelihood of receiving selected procedures to residence type. While this is a valid concern, we attempted to address it by risk-adjusting for various types of disability. Likewise, a systematic difference in coding across residences may affect the validity of our conclusions. The most likely difference in coding, however, would be in how disability is reported. For example, family members may be more prone to under-report the severity of certain disabilities or limitations, due to gradually becoming more accustomed to them. The overall pattern of disparities in receipt of preventive services that we found, however, does not change very much whether disability is controlled for or not. This particular possibility is thus likely not a big concern for validity of the conclusions drawn.

Policy efforts to assure that people with MR/DD receive necessary preventive care need to be appropriate to the mechanisms involved in the disparities, particularly for those living in their own home or with families. Solutions may include increased training for family members and staff, as well as for medical providers. While necessary, it will likely not be sufficient. Particularly for family caregivers, additional assistance and supports may be needed. These supports may include transportation and help in physically getting the person to the doctor, assistance in finding a physician, and appointment reminders. For non-family caregivers, improved wages and required credentials may assure greater continuity and attention to the needs of residents. Another important tool may be structured financial incentives for both caretakers and physicians. There also needs to be increased coordination among agencies providing services to people with MR/DD, as well as all those agencies and the physicians. A fundamental and

therefore essential change that also needs to occur is the shift in the persistent negative attitudes towards people with intellectual and developmental disabilities.

However, the problem of assuring adequate preventive health care for this population precludes easy solutions. Advocates, caretakers, and providers have struggled with how to best provide quality health care services while also supporting independence and self-determination. People with MR/DD living in institutions may receive better preventive health care services, but people living in communities and/or with families fare better on a range of other measures, most important of which is quality of life. It is important to remember that preventive health care, while important for this population, is not a sole or even overriding consideration. It is not a viable answer to go back to institutional-type arrangements. Instead, solutions need to be found and supports put in place that will allow people with MR/DD to receive adequate preventive health care without jeopardizing their rights and quality of life.

VIII. Limitations

There were limitations in our research. The most serious of them was the lack of utilization data through private insurance. We were able to capture only the procedures that were billed to Medicaid and Medicare. If a person had private insurance that paid for the preventive procedure of interest or if he/she paid out of pocket, his/her receipt of that preventive service could not be captured in our measures. While a relatively small percentage of the adult MR/DD population is likely to have private insurance, it is certainly possible that private insurance plays a role for at least some of the recipients. Furthermore, if having private insurance is not random for our population, it may bias our results and make them overly conservative. Since it is expected that the less disabled persons are more likely to have private insurance (through an employer, for example), we have a higher chance of having missing utilization information for the less disabled people in our sample. As such, our measured rate of receipt of preventive procedures is likely to be too low and the difference in rates for the most disabled and least disabled people in our sample too small. Thus, the effect of disability on the likelihood of receiving preventive health care may be even greater than our estimates indicated.

It is possible that we were not sufficiently rigorous in tracking down all the CPT and HCPCS codes used by Medicaid and Medicare in 2001-2002 to indicate our selected procedures. While this would bias the overall estimates of proportion of people receiving the procedures, it would not affect our conclusions about disparities by place of residence. However, if the incidence numbers are to be interpreted directly, for example

to compare with utilization rates of general population, more care will need to be taken to ensure that all possible codes are accounted for.

Also likely affecting the overall estimates, but not the conclusions about disparities by type of residence, is our choice of the length of observation time window. We chose a one-year window because most of the selected preventive services are, in fact, recommended to be administered once a year. Some, however, do not have such a clear-cut recommendation. A pap smear, for example, is recommended by many doctors to be performed once every 1-3 years, depending on age and other risk factors. Selecting a different observation window will certainly raise the estimates of received procedures and in some cases may result in more appropriate and informative markers for the amount and quality of preventive health care received by this population. A very important and widely used indicator for utilization of preventive health care that we did not consider in this study is a visit to a physician (for any reason). This should be explored in further research.

Another potential limitation is that a person's living situation was measured at the end of the follow-up period. An individual may not have remained in the same residential setting during the entire follow-up period. It's possible, for example, that a person lived in a family home for the first 10 months and then moved to a community-based group home. When consumers did change residences, the majority tended to move from family homes to foster/group homes. This may have led to the gap in likelihood of receipt of preventive care between foster/group home residents and family home residents being even wider than what we estimated. Exploration of available data,

however, indicated that switching of residential situation occurred relatively infrequently during the follow-up period (less than 5% of cases) and is not likely to affect the results to any significant degree.

Furthermore, our inability to distinguish between smaller and larger institution-like ICF/MRs likely led us to underestimate the actual magnitude of differences between ICF/MR residents and community-based residents, particularly in comparisons with people living in foster/group homes.

We measured disability at the end of the follow-up period. There is no guarantee that the person had the same level of disability during the entire observation period. This is likely not a big problem, however, since examination of DD assessments showed that a person's disability levels as measured by us rarely change during such a short timeframe.

An issue to consider is our choice of preventive health care measures. We picked our measures based both on recommendations for what preventive services are important for people with mental retardation/developmental disabilities and the kind and extent of data available to us. Furthermore, our cumulative preventive care measure weighed all preventive services equally. Some preventive health services may certainly be more important to the patient than others. However, the general consistency in our findings across different preventive health services allows one to draw broad conclusions about the effects of interest. It is also important to note that findings concerning preventive health care do not necessarily translate into conclusions about the quality of overall health care. It is certainly possible that the level of disability has no effect on receipt of

acute health care services, or that people living with families receive acute services at the same or even greater rate than people living in institutions such as ICF/MRs.

IX. Further research

Further research should tackle the problem of improving access to preventive health care in community-based residences. In order to start improving access to care, it is necessary to know what factors are responsible for existing barriers. The following questions are posed as possible directions for further research into isolating the relevant factors that may be amendable to interventions:

- Explore which, if any, characteristics of group homes as residential placement predict receipt of preventive health care.
- Explore which, if any, characteristics of family homes as residential option predict receipt of preventive health care.
- Explore which, if any, characteristics of the recipient's social worker predict receipt of preventive health care.
- Explore which, if any, characteristics of the county where the recipient resides predict receipt of preventive health care. This can be done using various hierarchical linear models, which can account for both observed and unobserved county-level characteristics. The general form for the basic HLM model is a set of equations such as follows:

$$Y_{ij} = B0_j + B1_j * X1_{ij} + B2_j * X2_{ij} + r_{ij}B0_j = G00 + G01 * W0_j + u0_j$$

$$B1_j = G10 + G11 * W1_j + u1_j$$

$B_{2j} = G_{20} + G_{21} * W_{2j} + u_{2j}$ W_{0j} , W_{1j} W_{2j} are county-level characteristics and X_{1ij} and X_{2ij} are recipient-level characteristics. One type of such models is spatial hierarchical modeling, fit using WinBUGS statistical package.

- Explore whether characteristics of physicians affect the receipt of preventive health care.
- Procure a more recent sample and explore whether recipients participating in Consumer Directed Community Support program (CDCS) are more likely to receive preventive health care.
- Explore whether place of residence has an effect on acute health care and high health care utilization overall.
- Using quartiles to test for threshold effect is a subjective and crude method. Use other methods to test for non-linear relationships between level of disability and receipt of preventive care. Perform additional analyses for threshold estimation.
- Perform additional analyses to investigate whether race is equally important in all residential settings.
- Perform additional analyses to investigate whether disability is equally important in all residential settings (interaction of residence and disability).
- Investigate whether more preventive health care leads to better health care outcomes in adults with developmental disabilities.

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Appendix 1. Very brief summary of how the developmentally disabled were treated throughout history.

In ancient Greece and Rome, infanticide was a common practice and infants and young children exhibiting signs of mental retardation were swiftly dealt with. In Roman Empire in the 2nd century A.D. (and even later in Medieval Europe) adults and children with mental retardation were often sold for entertainment or amusement. With advent of Christianity, treatment by society became somewhat more humane. In fact, all of the early religious leaders, Jesus, Buddha, Mohammed, Confucius, advocated humane treatment for the mentally retarded, or the infirmed (Sheerenberger, R. C., 1983).

During the Middle Ages in Europe the treatment and care of people with mental retardation varied greatly. Although more humane practices, such as establishment of orphan homes, evolved, many children were sold or abandoned. Most people with mental retardation lived in monasteries, hospitals, charitable facilities, prisons, almshouses, workhouses, etc. The oldest mental asylum providing continuous service in Europe was established as such in 1377 by the Church of Bethlem in England (it became known as “Bedlam”) and “catered” to both people with mental retardation as well as people with mental illness. Among its’ inventory at the end of 14th century were manacles, irons and stocks.

In the U.S. social conditions for people with mental retardation were perhaps somewhat better. In 1751, the first hospital in Philadelphia dedicated a separate section for people with mental retardation and people with mental illness. By 1756 the same hospital put its’ patients on display for a slight fee. The first hospital solely for “these miserable Objects who cannot help themselves” opened in Williamsburg, Virginia in 1773. In 1818 the American Asylum for the Deaf and Dumb in Hartford, Connecticut, began to provide the first recognized residential service intended specifically for people with mental retardation. The U.S. Census of 1840 for the first time attempted to measure the extent of mental illness and mental retardation by including the category “insane and idiotic” (Sheerenberger, R. C., 1983).

A key event in the evolution of care of the mentally retarded happened in the first decade of the 19th century when French physician Itard developed a broad education program for a boy named Victor who lived his whole life alone in the woods. Based on his method and under his supervision, Edouard Seguin developed a comprehensive approach to the education of children with mental retardation, known as the Physiological Method. In 1850, Seguin moved to the U.S. and became a driving force behind the education of individuals with mental retardation and in 1876 founded what would be known as the American Association on Mental Retardation (name recently changed to American Association on Intellectual and Developmental Disabilities). Many of his techniques, though modified, are still in use today.

In the early part of the 20th century, it became possible to measure a person's intelligence (or so it was believed) by using the Binet intelligence test translated and published in U.S. by Henry Goddard in 1908. It became possible to diagnose mental retardation. Residential training schools were began being established in most states and persons "diagnosed" with mental retardation were enrolled in large numbers in order to be "cured". By the 1920s, most states had state institutions. When these schools were unable to "cure" mental retardation, they became overcrowded. Many of the students were moved back into society. For the ones that remained, the training schools, which were initially more educational in nature, became custodial living centers. People immigrating into U.S. through Ellis Island were screened for mental defects and admittance was refused if such indications were found. Institutionalized residents with mental retardation were forcibly sterilized. The sterilizations continued until 1955.

As a result of disillusionment with residential treatment and wide reports of abuse in residential centers, advocacy groups began to be established in the U.S. in the 1950's. The Association of Friends and Parents of the Mentally Retarded (now The Arc) was one of the first parent organizations to campaign for opportunities other than institutionalization. Minnesota was a pioneering state in that as a part of this movement, Minnesota governor Luther Youngdahl (1947-1951) started the development of community-based mental health services and humane treatment for people in state institutions. In 1963 President Kennedy proposed and signed legislation that started

community mental health center movement to substitute comprehensive community care for custodial institutional care nationwide. Parallel developments for people with mental retardation and developmental disabilities, however, were still somewhat lagging. Beginning with the landmark law suit in Pennsylvania (the Wyatt-Stickney federal court action) in the 1970's which established the right to treatment of individuals living in residential facilities and defined purely custodial care as unacceptable (Biasini F.J., Grupe L., Huffman L., et al), and the 1977 ruling by U.S. District Judge Raymond Broderick that keeping people with mental retardation in institutions was a violation of their constitutional rights, a number of similar suits were filed across the country and brought the concept of deinstitutionalization to the forefront (Cooke, Virginia). A very important lawsuit (the first of its kind) - Pennhurst State School and Hospital vs. Haldermann - was brought in 1986 by a former resident of an institution and asserted that people with mental retardation had a right to habitation and a right to treatment in the least restrictive environment and that Pennhurst was not fulfilling those rights. This lawsuit led to the closure of that institution.

Appendix 2. MR/DD Waiver state and county responsibilities in Minnesota.

According to Minnesota Department of Humans Services, the responsibilities of the state for Waiver management are to:

- “ - respond to the State Legislature for development of Waiver programs and services;
 - design and develop services in order to obtain federal participation in the Waiver programs;
 - develop policy that expresses program and department goals;
 - centrally manage county administration of the programs for statewide consistency and compliance with federal standards;
 - act as a policy and technical resource for counties;
 - monitor program activity to assure the integrity of services and standards;
 - provide annual reports to CMS on the performance of the Waivers;
 - assist CMS in audits of the programs prior to the five-year program renewal cycle;
 - renew Waiver programs as required by the Centers for Medicare & Medicaid Services.”

In addition, DHS “and county social service agencies maintain an active investigative force to resolve any report or incident that relates to abuse, neglect or maltreatment of vulnerable persons. Incident reports require immediate response by the county agency to investigate and provide follow-up. DHS has policies and procedures in place to receive regular reports regarding the alleged action and outcomes of investigations” (Disability Services Program Manual, MN DHS). In contrast, “local county administration, acting as agents for the state Medicaid agency (DHS) provide the following:

- case management/service coordination for persons receiving services including assessment and service plan development; assistance to help people access, coordinate and evaluate available services;
- determine financial and program eligibility of persons for services and programs;

- input of consumer enrollment data (screening document) and service authorization into MMIS (Minnesota's automated Medicaid Management Information System);
- authorize and monitor services to reasonably assure health and safety;
- monitor the on-going provision of services for efficacy, consumer satisfaction, continued eligibility, adjusting as necessary;
- contract management and supervision of services;
- sign provider agreements with DHS to assure that all providers meet State standards for licensing or certification relevant to their area of service;
- systematic monitoring of provider performance;
- work in partnership with DHS and other organizations to provide information, services and assistance to people with disabilities" (Disability Services Program Manual, MN DHS).

Counties also negotiate contracts with providers of Waiver services and set rates paid to these providers.

Appendix 3. Descriptive analysis of disability and place of residence by age.

The age range at the time of assessment was from 18 to 101 years, with mean of 40.1 years, median 38.0 years, and standard deviation 15.7 years. The histogram of the age distribution is presented in Figure 3.1.

Figure 3.1. Age distribution

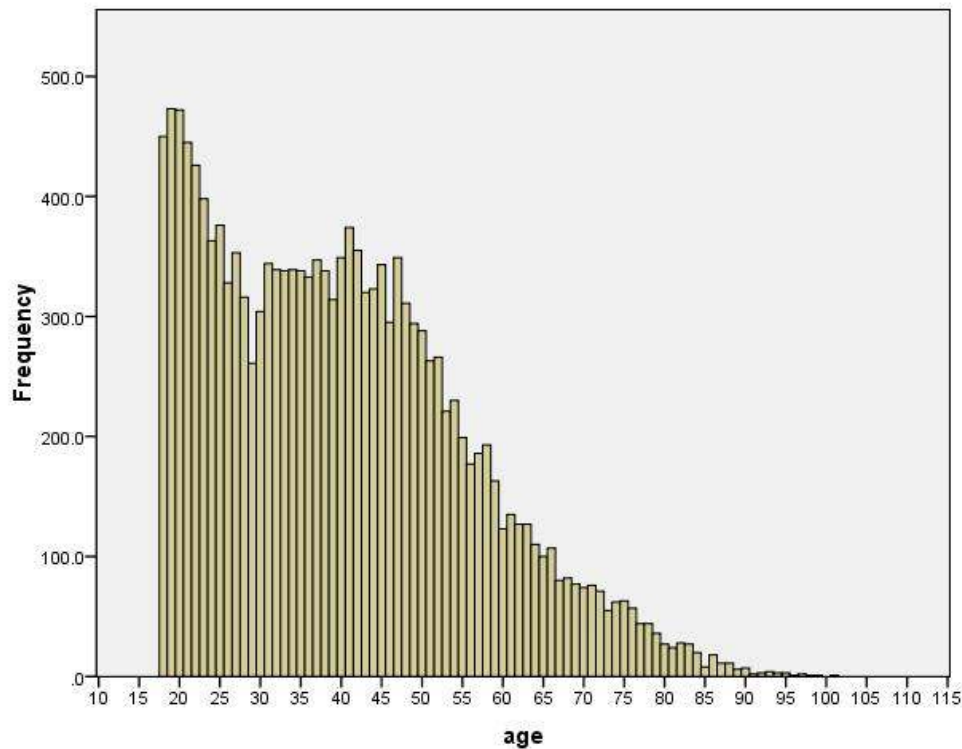


Table 3.1 presents means and standard deviations of disability scales, percentages in categorized disability scales, and percentages of people in different residential arrangements and programs for age grouping. Age groupings are as follows: 18-25, 26-35, 36-45, 46-55, 56-65, 66-80, and 81+.

The majority of younger people (18-25) live in family homes, with percentage remaining in family homes dropping off steadily the older people get. After the age of 25 and through the age of 80, around 50% live in foster homes. After the age of 80 a large proportion shifts to other/unknown residence, which includes nursing homes. The proportion of those living in ICF-MRs increases with age, with the largest jump occurring

somewhere between ages 25 and 45 (10.1% of those aged 26-35 are in ICF-MRs as compared to 19.3% of those aged 36-45), after which the percentage living in ICF-MRs seems to more or less stabilize. The peak number of people living in their own home seems to occur between ages 26 and 45, after which the proportion gradually drops off. The drop-offs in later ages of own home residence, family home residence, and foster home residence seem to be balanced by an increase in other/unknown (including SNFs) residence.

As one would expect, both ADL and physical disability seem to increase for those over 65 years of age. On the other hand, both legal and illegal behavior disability seem to decrease for those 65 and older. This, may be due to the fact that both behavior scales contain items that measure behaviors observed – “does the person do this”. With age-related increased physical disability the person may not be able to actually perform actions measured by the behavioral items (such as running away, being physically aggressive, breaking the law, etc) and as such these behaviors may not be observed anymore. Interestingly, larger percentages of people fall into more cognitively disabled categories, particularly into the severe category, with age progression. This may be due to early onset Alzheimers or other such dementia-related diseases that many people with MR/DD are particularly at risk for.

Table 3.1. Disability and age

	18-25 yrs (mean/s.d.)	26-35 yrs (mean/s.d.)	36-45 yrs (mean/s.d.)	46-55 yrs (mean/s.d.)	56-65 yrs (mean/s.d.)	66-80 yrs (mean/s.d.)	81+ yrs (mean/s.d.)
ADL disability	37.9 / 10.9	36.6 / 11.5	37.5 / 11.0	39.8 / 10.8	40.8 / 10.8	43.2 / 9.8	47.5 / 8.4
Quartile 1	30.3%	35.2%	31.3%	22.6%	21.1%	13.1%	5.0%
Quartile 2	30.0%	28.3%	28.6%	28.4%	27.0%	21.9%	15.5%
Quartile 3	23.3%	21.4%	24.5%	28.2%	28.8%	40.3%	36.5%
Quartile 4	16.0%	14.8%	15.5%	20.6%	23.0%	24.5%	42.5%
Legal Behavior disability	14.6 / 10.5	13.6 / 9.6	14.3 / 9.8	14.6 / 9.8	13.5 / 8.5	13.0 / 8.1	11.7 / 7.7
Quartile 1	29.2%	28.0%	25.3%	23.2%	24.8%	23.0%	32.0%
Quartile 2	26.7%	31.2%	30.5%	30.5%	31.1%	35.5%	33.1%
Quartile 3	17.0%	18.8%	19.2%	21.6%	22.0%	23.5%	22.1%
Quartile 4	26.8%	21.9%	24.9%	24.7%	21.9%	18.0%	12.7%
Illegal Behavior disability	5.4 / 4.4	5.0 / 3.8	5.0 / 3.9	4.7 / 3.3	4.3 / 2.7	4.0 / 2.5	3.6 / 1.6
None	62.4%	63.7%	63.3%	65.4%	70.4%	77.5%	84.5%
Mild	20.8%	24.0%	24.6%	24.3%	22.6%	16.9%	11.6%
Mod/Severe	16.4%	12.1%	11.8%	10.2%	6.9%	5.7%	3.3%
Cognitive disability (ICD-9)	-	-	-	-	-	-	-
Mild	40.5%	42.4%	39.0%	36.2%	37.1%	37.4%	40.3%
Moderate	32.9%	28.2%	24.3%	21.6%	22.4%	22.7%	18.8%
Severe	12.1%	14.8%	17.8%	19.5%	21.0%	23.6%	30.4%
Profound	7.2%	11.4%	17.4%	21.4%	18.4%	15.2%	9.9%
Communication disability	7.1 / 5.2	7.1 / 5.2	7.8 / 5.6	8.3 / 5.6	8.2 / 5.4	8.5 / 5.2	8.9 / 5.4
Quartile 1	34.1%	35.6%	29.9%	25.4%	24.0%	15.6%	11.0%
Quartile 2	22.1%	21.3%	23.0%	21.6%	20.1%	22.4%	22.1%

Quartile 3	21.6%	19.9%	19.8%	21.9%	26.0%	33.7%	38.1%
Quartile 4	20.0%	21.3%	25.5%	28.8%	26.7%	26.1%	24.9%
Physical disability	8.8 / 6.5	8.2 / 6.2	7.7 / 5.8	8.4 / 6.1	8.8 / 6.2	9.6 / 5.8	10.8 / 5.6
Quartile 1	28.5%	34.0%	36.0%	29.7%	25.7%	15.1%	7.2%
Quartile 2	23.4%	21.2%	22.3%	23.7%	24.8%	22.8%	21.0%
Quartile 3	20.3%	20.3%	20.4%	21.1%	20.7%	31.0%	32.6%
Quartile 4	27.1%	23.5%	20.4%	24.2%	27.5%	30.1%	38.7%
Residence							
ICF-MR	4.4%	10.1%	19.3%	21.4%	20.5%	23.2%	19.9%
Family home	56.6%	29.6%	17.3%	13.2%	10.2%	7.5%	6.1%
Foster/group home	32.5%	47.3%	49.6%	51.3%	53.4%	45.7%	38.1%
Own home	4.0%	10.7%	10.6%	9.1%	8.0%	5.0%	1.1%
Other/unknown	2.6%	2.4%	3.1%	5.1%	7.9%	18.5%	34.8%
Program							
CDCS	19.7%	10.6%	7.1%	4.8%	3.3%	2.2%	0.6%
SILS	2.2%	4.1%	3.9%	3.4%	2.8%	1.5%	0.0%
Neither/ unknown	78.0%	85.2%	89.0%	91.8%	93.9%	96.3%	99.4%
N	3,403	3,260	3,396	2,716	1,441	955	181