DEVELOPMENT OF A HEALTH ASSESSMENT INSTRUMENT FOR ADULTS WITH MENTAL RETARDATION

by

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This project resulted in the development of a new caregiver-administered health assessment instrument, Let's Get Healthy Together!, for adults with mental retardation who live with their families. The instrument, which consists of 64 questions over 20 pages and has a completion time of about 17 minutes, addresses a wide range of health issues, including oral health, social supports, preventive screenings, diet, exercise and smoking. This project is of public health significance as health disparities exist for those with mental retardation compared to the general population. This instrument can address those disparities on two levels: individually to identify health concerns that may need further attention, and on a large scale to identify population based health issues that may merit intervention on a systemic level.

The project was undertaken in cooperation with, and for the benefit of, the Commonwealth of Pennsylvania Office of Mental Retardation (OMR). The instrument was developed based on a qualitative study of the health issues and risk factors for this population, using focus group and telephone interviews with caregivers and individuals, a literature review, and expert interviews. A pretest, consisting of telephone and expert interviews, was conducted, and a final version of the instrument prepared.

The primary finding from the preliminary research done with caregivers was that while most saw no benefit in using a health assessment instrument, a subset of them who later tested

the Let’s Get Healthy Together! instrument, relayed comments that were very positive overall. The only negative reaction was that the instrument was not comprehensive enough to address the specific clinical needs of someone with Down syndrome. Participants expressed greater concern with systemic issues and barriers, such as the quality of the health care system, than for the individual issues for their family members.

The instrument that is presented to OMR addresses the primary health issues and risk factors for adults with mental retardation. Further pretesting, and a comprehensive pilot test, is recommended before implementing the Let’s Get Healthy Together! instrument.

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PREFACE

I would like to thank the following people for supporting me in this journey. All of you have made a difference by sharing in the significant effort that completing this task required.

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1.0 INTRODUCTION AND STATEMENT OF THE PROBLEM

1.1 INTRODUCTION

The concept of health disparities in public health is generally considered in relation to racial and ethnic minorities. In recent years, it has become increasingly evident that there are also health disparities for adults with mental retardation. While the existing base of knowledge of health disparities in mental retardation is limited, the area is receiving increased attention among researchers and government officials.

Historically, people with mental retardation have been subjected to imprisonment (Dix, Dorothea L., 1845), they been the subjects of risky research studies, including the early polio vaccine trials (Brandt, Allan M., 1979), they have had their right to give birth taken from them (Hackbush, Florentine, 1932; Popenoe, Paul & Johnson, Roswell Hill, 1920; Lombardo, Paul, 2002) and they have been forced to leave their homes and communities for the shelter of government run or sponsored asylums (Kirkbride, Franklin B, 1912). Concern for the adequacy of community-based health care for people with mental retardation is a recent phenomenon (Rimmer, J. H., 1999).

This dissertation describes the development of a health assessment instrument for use with adults with mental retardation who live with their families. It will fill a gap in the literature, as there are few currently available instruments, and those that do exist have been developed for a narrow purpose or target group, designed for administration by a clinician, or are otherwise not suitable for this purpose. The project was conducted with support from, and for the benefit of, the Commonwealth of Pennsylvania Office of Mental Retardation, an office within the Department of Public Welfare.

The goal of the project was to develop an instrument to accurately assess the health of adults with mental retardation who live with their families, thereby providing a mechanism for improved communication with health care providers and improved identification of individual and aggregate health concerns.

1.2 STATEMENT OF THE PROBLEM

1.2.1 Historical Perspective

In the pre-industrial revolution years of the United States, people with mental retardation were able to blend into the population and fill valued roles in society. As the country became more complex and struggled with economic turmoil and social unrest following the civil war, people with mental retardation became easy targets for those seeking answers to the problems of the day. Many were jailed or housed in the earliest hospitals, and placed on public display for entertainment purposes (Dix, Dorothea L., 1845; Sudak, Howard MD, 2002). In the mid to late 1800's, inspired by European educators who claimed to be able to cure mental retardation (or idiocy, as it was referred to at the time), large schools were developed to educate people with mental retardation so that they could be returned to society and become productive (Howe, S. G., 1848). The operators of these schools soon realized that their task was bigger than they imagined (Adams, Margaret, 1971). Schools quickly became custodial institutions, and the goal of education deteriorated to one of warehousing and later, in the pre-WWII years of the American eugenics movement, population control (Hackbush, Florentine, 1932; Barr, Martin W., 1904; Allen, Garland E., 2002).

Beginning in the 1950's, and later inspired by the civil rights movement and strong consumer advocacy efforts in the area of mental illness, parents and advocates began to demand improved quality of care in institutions, public education for all children, and the availability of services in the community. Federal resources became available (Congressional Research Service, 1993; President's Committee on Mental Retardation, 1977; President's Committee on Mental Retardation, 1976), a community service system developed, and the nation's institutions began to empty. In 1967, 195,650 people with mental retardation nationwide were institutionalized in state facilities, but by 1997 that number had dropped to 56,161 (Anderson, Lynda L., Lankin, K. Charlie, Mangan, Troy W., & Prouty, Robert W., 1998). In Pennsylvania, the institutional population declined from over 13,000 in 1967 to less than 2,000 by the end of the 20th century (Commonwealth of Pennsylvania, 2000). Not everyone supported deinstitutionalization, however, as some families advocated for preservation of what they felt was a safer housing option for their family members with mental retardation.

1.2.2 Health Disparities and Mental Retardation

During the early years of rapid deinstitutionalization, the health issues of adults with mental retardation received relatively little attention. In the 1990's, a series of well publicized deaths in community residential programs bolstered the position of those who fought to preserve institutions (Lempinen, Edward W, 1997a; Lempinen, Edward W, 1997b; Lempinen, Edward W, 1997e; Lempinen, Edward W, 1997d; Lempinen, Edward W, 1997c; Bennish, Steve & Beyerlein, Tom, 2002). The controversy was further fueled by a bitter debate over conflicting comparative mortality studies -- some which found significantly higher mortality rates in community settings as opposed to institutions (Strauss, D., Shavelle, R., Baumeister, A., & Anderson, T. W., 1998; Shavelle, R. & Strauss, D., 1999), and others which found the opposite (O'Brien, K. F., Tate, K., & Zaharia, E. S., 1991; Conroy, J. W. & Adler, M., 1998).

One welcome result of that heated debate was a new focus on the health of people with mental retardation in the academic, public health and advocacy communities. Researchers examining the health status of people with mental retardation found higher risk for certain chronic conditions, high rates of obesity and inactivity, high rates of previously unidentified conditions, barriers to accessing health care, and other related problems (van Schrojenstein Lantman-De Valk HM, Metsemakers, J. F., Haveman, M. J., & Crebolder, H. F., 2000; Rimmer, J. H., Braddock, D., & Fujiura, G., 1993; Beange, H., McElduff, A., & Baker, W., 1995; Sutherland, G., Couch, M. A., & Iacono, T., 2002). These alarming findings generated attention from the federal government, resulting in a 2002 report of the Surgeon General of the United States entitled: *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (US Public Health Service, 2001), which highlighted far-reaching concerns about the quality of health care provided to people with mental retardation.

Tommy G. Thompson, Secretary of the United States Department of Health and Human Services, stated: “Americans with mental retardation, and their families, face enormous obstacles in seeking the kind of basic health care that many of us take for granted”, “American health research, the finest in the world, has too often bypassed health and health services research questions of prime importance to persons with mental retardation,” and “Individuals with mental retardation are more likely to receive inappropriate and inadequate treatment, or be denied health care altogether." (US Public Health Service, 2001) National goals set forth in the document included integrating health promotion programs into mental retardation supports, increasing knowledge of health issues for those with mental retardation, improving the quality and availability of health care, training health care providers, and addressing health care financing issues that may serve as barriers to accessing health care.

For a variety of reasons, including ethical concerns related to research procedures and consent, much of the available research on the health needs of people with mental retardation is methodologically weak, with heavy reliance on small group case studies and convenience samples (Oliver, P. C. et al., 2002). The study of health care for people with mental retardation is clearly in its infancy (Horwitz, Susan, Kerker, Bonnie D., Owens, Pamela L., & Zigler, Edward, 2000; Traci, M. A., Seekins, T., Szalda-Petree, A., & Ravesloot, C., 2002), and the lack of health assessment instruments for use in this population is indicative of this weakness.

2.0 LITERATURE REVIEW

2.1 OVERVIEW OF MENTAL RETARDATION

2.1.1 Definitions

There is no universal definition of mental retardation, complicating efforts to understand the subject and build a body of research (Prasher, VP. & Janicki, M. P., 2002). The existing definitions include common elements of deficits in intellect and functional skills, and manifestation during the developmental period. As of 2006, the term mental retardation is used in the United States, while most of the world uses either intellectual disability or learning disability (Hamilton-Kirkwoode, L., 2002). On January 1 2007, The American Association on Mental Retardation (AAMR) will change its name to American Association on Intellectual and Developmental Disabilities (AAIDD), at which time it will abandon the term mental retardation in favor of intellectual disability (American Association on Mental Retardation, 2006).

AAMR Definition. The most recent (2002) definition of the American Association on Mental Retardation (AAMR) refers to mental retardation as a disability characterized by significant limitations in intellectual functioning and adaptive behavior, manifested before the age of 18. (American Association on Mental Retardation, 2002). AAMR describes mental retardation as a state of functioning that is reflective of the gap between individual functioning and environmental expectations, and not a condition or a disease.

The determination of intellectual functioning relies on an IQ score assessed using a standardized instrument that is administered by a trained professional. A score of 70 or below, two standard deviations below the mean of 100, is generally considered to reflect an intellectual deficit. The AAMR takes into account measurement error, and permits an IQ of 75 or above in the presence of a functional limitation as long as it is manifested before the age of 18.

Deficits in adaptive behavior are assessed using standardized tests such as the Vineland Adaptive Behavior Scales (Sparrow, Sara, Balla, David, & Cicchetti, Domenic, 1984), with a deficit occurring when an overall score is at least two standard deviations below the mean, or when there is a significant limitation in one of three categories of adaptive behavior. AAMR classifies adaptive skills into three categories -- conceptual (reading and writing, money use, etc.), social (self-esteem, responsibility, following rules, etc.), and practical (eating, dressing, toileting, preparing meals, etc.).

United States Social Security Administration (SSA) Definition. The SSA definition, used to determine benefit eligibility, differs from that of the AAMR. The SSA definition uses an upper age range for manifestation of 21 instead of 18. It also considers partial (verbal or performance) IQ scores in the determination of an intellectual limitation. Finally, it considers the combination of an intellectual deficit with a comorbid medical or psychiatric disorder to be mental retardation for the purpose of eligibility (Reschly, D. J., Myers, T. G, & Hartel, C. R., 2003).

OMR Definition. The Commonwealth of Pennsylvania Office of Mental Retardation (OMR) adapts the definition in the Diagnostic and Statistical Manual (DSM) IV (American

Psychiatric Association & Task Force on DSM-IV, 1994) for use in determination of eligibility for mental retardation services in Pennsylvania. The DSM considers mental retardation to be significant sub-average intellectual functioning combined with significant adaptive functioning deficits in two skill areas (such as communication, self-care, work, leisure, etc.), with an onset before the age of 18. OMR uses the DSM definition, but extends the age up to 21 (Commonwealth of Pennsylvania Department of Public Welfare, 2002). The OMR definition of mental retardation will be used in this study.

2.1.2 Prevalence

Approximately 1 – 3 % of the population in the United States has mental retardation, with approximately 85% thought to be in the mild range (Rubin, I. Leslie & Crocker, Allen C, 1989; The Arc of the United States, 1998; World Health Organization, 2001). The varying prevalence estimates are related to the lack of a universal definition and methodological differences (Larson, S. A. et al., 2001) between prevalence studies. The causes of mental retardation are numerous and varied, and include genetic conditions, maternal substance abuse, poverty, cultural deprivation, and problems during pregnancy or birth (American Association on Mental Retardation, 2002).

2.1.3 Mental Retardation and Related Conditions

Mental retardation is, generally, one of a family of disorders under the umbrella of developmental disability, but it is possible to have mental retardation and not a developmental disability and it is possible to have a developmental disability and not mental retardation. The

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (106th Congress, 2000) defines developmental disability as a severe, chronic disability attributable to a mental or physical impairment, or a combination of mental and physical impairment, that is manifested before the age of 22, is likely to continue indefinitely, results in substantial functional limitations in 3 or more areas of major life activity, including learning, mobility, and economic self-sufficiency, and results in a need for individually planned lifelong services or supports of extended duration.

In the 1994 and 1995 administrations of the National Health Interview Survey Disability Supplement (NHIS-D), 28% of those meeting the criteria for either mental retardation or developmental disability had both conditions, 24.3% had mental retardation but not a developmental disability, and 47.7% had a developmental disability but not mental retardation.

The term developmental disability generally refers to conditions such as cerebral palsy, autism, epilepsy, and Down Syndrome, and these (related) conditions are associated with mental retardation. It is possible, however, to have one of these conditions and not meet the formal definition of a having a developmental disability.

It is frequently the related conditions that place an individual at higher risk for poor health. For example, it is known that individuals with Down Syndrome are at higher risk for congenital heart defects, visual impairments, and thyroid dysfunction (Cohen, William I., 1996; van Allen, M. I., Fung, J., & Jurenka, S. B., 1999). Although a very small number of individuals with Down Syndrome do not have mental retardation (National Down Syndrome Congress, 2004), it is the most common known cause of mental retardation (Galdzicki, Z., Siarey, R., Pearce, R., Stoll, J., & Rapoport, S. I., 2001).

It is expected that the health risks faced by individuals with mental retardation will be a composite of the risk faced by the general population, risk resulting from the related conditions that an individual may have, and risk related to mental retardation, such as individual functional limitations along with social and environmental barriers to accessing health care and maintaining good health.

2.2 HEALTH AND MENTAL RETARDATION

2.2.1 Mortality

Numerous studies have found increased mortality for individuals with mental retardation compared to the general population. O'Brien, Tate and Zaharia found higher mortality rates in a large institution in the southeast United States compared to the surrounding county during the period from 1974 through 1985. Mortality at the facility decreased over time, which they attributed to a reduction in census due to deinstitutionalization, increased staffing, and the attainment of ICF/MR and accreditation status with increased medical and active treatment requirements. Respiratory disease was the most common cause of death, particularly for those with more severe intellectual impairment, followed by heart disease and cancer (O'Brien, K. F., Tate, K., & Zaharia, E. S., 1991).

Eyman et al. explored the risk factors for mortality in two groups of individuals admitted ten years apart, in 1970 and 1980, to a large institution in California. They found increased mortality over that time, but the groups differed significantly in several ways. The 1980 group was sicker and more limited intellectually, and had higher proportions of the very young and very old. The most common cause of death was respiratory disease. The study concluded that risk factors for increased mortality were age (very young or very old), low IQ, non-ambulation, epilepsy, tube feedings, and higher use of health care services including hospitalizations, clinic visits, and laboratory tests (Eyman, R. K., Chaney, R. H., Givens, C. A., Lopez, E. G., & Lee, C. K. E., 1986).

Eyman, Call and White found that elevated risk of mortality was associated with decreased intellectual functioning, concluding that a lack of mobility or feeding skills were better predictors of death than the existence of a medical condition like congenital heart disease in people with Down Syndrome served by the state of California between 1984 and 1987 (Eyman, R. K., Call, T. L., & White, J. F., 1991). Strauss and Eyman found a relationship between intellectual function and mortality, when their study found that individuals below age 35 with severe intellectual impairments had increased mortality (Strauss, D. & Eyman, R. K., 1996).

A retrospective review of case records of all individuals with mental retardation who died at one large California institution between 1929 and 1989 resulted in a conclusion that those most at risk had more severe intellectual impairment, were younger, had poor mobility and feeding skills, had more medical complications, and were more likely to have a prenatal etiology of brain damage (Chaney, R. H. & Eyman, R. K., 2000).

A comprehensive community based mortality study was conducted in Finland in 1997, using the records from a large, population based study started in 1962 to investigate the prevalence of intellectual disability and the need for services. Findings were that cardiac and respiratory diseases and neoplasms were the most common causes of death for those with intellectual disability, the same as for the general population with the exception that neoplasms were more prevalent than respiratory diseases in the general population than they were for individuals with intellectual disabilities. Mortality was elevated for those with more severe intellectual disabilities and for those less than 40 years of age with respiratory, digestive and infectious diseases. Pneumonia was by far the primary case of death for those dying from respiratory disease, followed by COPD. Digestive diseases were 2.5 times more common than in the general population, with intestinal obstruction the primary cause. Males and those with profound intellectual disabilities were the most at risk. The risk of accident was lower than in the general population, but for accidents that did occur, moderate intellectual disability, age over 50 years, and placement either in community settings or mental hospitals were risk factors. Fractures resulting from falls or vehicle accidents were the most common cause of accidental death. Overall, mortality for those with milder disabilities over the age of 30 was similar to that of the general population (Patja, K., Molsa, P., & Iivanainen, M., 2001).

Janicki et al. examined records of 2752 adults age 40 or older who died between 1984 and 1993 in New York State. The causes of death mirrored that of the general population – cardiac diseases, respiratory diseases, and cancer. Janicki concluded that, while the gap in life expectancy between adults with and without intellectual disability narrowed during that time, adults with mental retardation had a shorter life expectancy of 66.1 years compared to 70.4 years, and adults with Down Syndrome had the shortest life expectancy, 55.8 years (Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W., 1999).

Starting in 1996, Dr. David Strauss and colleagues at the University of California, Riverside published a series of comparative mortality studies which found that individuals with mental retardation living in the community had higher mortality rates than those living in institutions, a finding that was not expected in light of the fact that those remaining in institutions were assumed to have had lower levels of intellectual functioning and more medical problems, both shown to be related to elevated mortality. In one study, Strauss, Eyman and Goldman found 25% higher mortality among children living in the community compared to those in institutions, with decreased mobility and tube feeding the risk factors for significantly increased mortality (Strauss, D., Eyman, R. K., & Grossman, H. J., 1996). In another, Strauss and Kastner found a 72% higher risk of mortality in the community, pointing to health care access issues in community settings to explain some of the variation (Strauss, D. & Kastner, T. A., 1996). Similar results were found by Shavelle and Strauss in a study published in 1999 (Shavelle, R. & Strauss, D., 1999). In another study, Strauss, Shavelle, Baumeister and Anderson studied mortality rates in almost 2000 individuals with mental retardation who moved from institutions into the community between April 1993 and March 1996. They found that mortality was 51% higher for those who left institutions, with risk highest in the first 60 days after the move (Strauss, D., Shavelle, R., Baumeister, A., & Anderson, T. W., 1998).

Other researchers conducting mortality studies found conflicting results to those found in the California studies, touching off a firestorm of debate and accusations on both sides about questionable methodology and motivations (Borthwick-Duffy, Sharon, Widaman, Keith F, & Grossman, Herbert J., 1998). In Pennsylvania, Conroy and Adler examined mortality in 1415 individuals who moved out of the Pennhurst State School in Philadelphia while it was being shut down, finding lower mortality than mortality predictions had Pennhurst remained open (Conroy, J. W. & Adler, M., 1998).

In another study conducted in New Jersey, researchers used a prospective research design to compare mortality in 150 individuals leaving state institutions compared to 150 who had remained. They found that the mortality rates were similar for the two groups after controlling for medical risk factors and concluded it was those factors that influenced mortality and not the location of residence. Those more at risk for elevated mortality were age 60 or above, those with medical conditions, low self-care scores, seizure disorders, and those who were placed in nursing homes (Lerman, P, Apgar, D., & Jordon, T., 2003).

Despite the controversy and the media frenzy that resulted (Borthwick-Duffy, Sharon, Widaman, Keith F, & Grossman, Herbert J., 1998), the comparative mortality studies did succeed in drawing attention to the health disparities faced by individuals with mental retardation and providing insight into areas of potential risk as well as a foundation for future research and health promotion efforts.

2.2.2 Morbidity

A number of researchers have found increased prevalence of diseases in adults with mental retardation. Some of these conditions fall into the category of secondary conditions, defined as additional physical or mental health conditions resulting from, and causally related to, having a disability (Pope, Andrew M & Tarlov, Alvin R., 1991). Much of the recent research in health for adults with disabilities focuses on the identification and prevention of secondary conditions (Rimmer, J. H., 1999; Marge, Michael, 1994; Traci, Meg Ann, 2000; Frey, L., Szalda-Petree, A., Traci, M. A., & Seekins, T., 2001; Wilber, N. et al., 2002; Simeonsson, R. J., McMillen, J. S., & Huntington, G. S., 2002). Secondary conditions only tell part of the story of the health risks for adults with mental retardation, many of whom do not have the types of physical disabilities that are commonly associated with secondary conditions, such as paraplegia that can result in pressure sores.

Janicki et al. used survey research to assess the health of a convenience sample of 1600 adults over 40 years of age in New York State in 1998 and 1999, using proxy respondents of nurses or case managers who were familiar with the individuals. Despite the fact that a large majority, 85%, reported being in good or excellent health, 49% reported visual impairments, 27% reported hearing impairments, over 50% reported being obese, half reported engaging in no exercise at all, 7% reported a bone fracture in the last year, and 10% experienced a fall resulting in tissue injury. 30% were treated in the ER in the previous year, and 16% were hospitalized. Tobacco use was 8% and alcohol use was less than 1%. Almost a quarter of all adults had nail, topical fungal and skin disorders, with greater prevalence among those with lower intellectual functioning or Down Syndrome. Gastrointestinal disorders were more prevalent in adults with cerebral palsy, adults with lower intellectual functioning, males, and with those with higher body mass index (BMI).

A comparison of these data with the National Health and Nutrition Evaluation Survey III (NHANES III) revealed that the individuals with mental retardation reported similar rates of diseases, and similar age-related increases in disease prevalence to the NHANES results, except that prevalence rates were significantly *lower* for cardiovascular and musculoskeletal diseases, hypertension, hyperlipidemia, and adult-onset diabetes in the Janicki sample. The authors concluded by voicing concern about possible under-reporting and under-recognition of disease in adults with mental retardation (Janicki, M. P. et al., 2002).

Kapell et al. interviewed caregivers and reviewed medical records for 278 adults with mental retardation in New York State in 1993 and compared the results to the 1993 National Health Interview Survey (NHIS). They found a higher prevalence of hypothyroidism, heart disorders and visual impairment in adults with mental retardation, with those with Down Syndrome having a higher frequency of thyroid dysfunction, cardiac disorders, and visual impairment. The authors recommended regular surveillance of health status along with increased access to primary and specialty health care for adults with mental retardation (Kapell, D. et al., 1998).

Beange et al. studied 202 adults with mental retardation living in community and institutional settings and using the services of one hospital-based health promotion clinic for adults with mental retardation in Australia. They found an increased prevalence of obesity, particularly in females, increased hypertension among the females, lower rates of exercise, increased sleep, and lower use of alcohol and tobacco. There were higher rates of sensory impairments (hearing and vision), epilepsy, untreated skin disorders, undiagnosed hypertension and congenital heart disease. 95% had associated medical conditions, with 40% having six or more conditions. 42% of the conditions were previously undetected, many had not received needed specialty care, and large numbers who did receive treatment were not adequately managed. The authors concluded that adults with mental retardation are at higher risk for poor health and should have increased access to health services and health promotion opportunities (Beange, H., McElduff, A., & Baker, W., 1995).

Minihan and Dean surveyed proxy respondents of 333 adults with mental retardation randomly selected from 1,333 individuals with mental retardation living in community settings in Massachusetts. They found that the top five chronic conditions were neurological (primarily epilepsy), visual, skin, psychiatric, and orthopedic. Over 31% reported more than one chronic condition and less than 40% of the women were reported to have had a gynecological examination in the previous three years. Barriers to obtaining health care included provider unwillingness to accept Medicaid and lack of cooperation of the individual with medical treatment (Minihan, P. M. & Dean, D. H., 1990).

The 1994 and 1995 NHIS-D surveys of individuals with intellectual and/or developmental disabilities indicated that people with intellectual disability but without developmental disability were 89% more likely to report unmet health needs than the general population, and those with both intellectual and developmental disabilities were three times as likely to report unmet health needs as the general population. Unmet health needs were also reported to be higher in those living in households below the poverty level, with race other than Caucasian, and with health less than good. People with intellectual disabilities had increased frequencies of short hospital stays and physician visits, and those with both intellectual and developmental disabilities were less likely to have dental care access and more likely to have unmet mental health needs (Anderson, L., Larson, S., Lakin, C., & Kwak, N., 2003).

2.2.2.1 Epilepsy

Individuals with mental retardation have a higher prevalence of epilepsy than the general population, although the rates vary widely. Morgan et al. determined the prevalence of epilepsy in 1595 people with intellectual disability to be 16.1%. They found also that individuals with mental retardation and epilepsy used both inpatient and outpatient services with greater frequency and had higher rates of accident and emergency admissions than those without epilepsy (Morgan, C. L., Baxter, H., & Kerr, M. P., 2003). Elia et al. found a prevalence rate of 44.45% in a case study of 63 children and young adults with mental retardation and autism in an institution in Italy, with females more likely to have epilepsy. McKee et al. found that adults with mental retardation and epilepsy residing in a public institution had a higher rate of sudden death than those without epilepsy, with risk factors of non-ambulatory status, poorly controlled seizure disorder, and increased number of antiepileptic drugs taken (McKee, J. R. & Bodfish, J. W., 2000).

2.2.2.2 Oral Health

Numerous studies have found a higher prevalence of poor dental health and increased barriers to accessing dental health for adults with mental retardation. A longitudinal study conducted in Israel between 1996 and 2001 by Lifshitz et al. found that 30% of participants residing in either community group homes or with their families had dental problems, with a higher prevalence of problems for those living with their families (Lifshitz, H. & Merrick, J., 2003). In a separate study, Lifshitz and Merrick compared aging related phenomenon in adults with intellectual disability living in group homes and families, finding that the group home residents had higher rates of medical problems, but the family residents had higher rates of dental problems. In both situations, individuals with Down Syndrome had higher rates of medical problems than those without. A possible explanation for the dental difficulties experienced by the families is that, according to the authors, in Israel the government arranges for and provides free dental care for those in residential programs, whereas those living with families must locate dental care on their own (Lifshitz, H. & Merrick, J., 2004).

Cumella et al. conducted survey research and direct examination with adults with mental retardation and their caregivers in the UK, finding higher prevalence than the general population of tooth decay, gum disease and missing teeth. Fifty-eight percent of those agreeing to the dental examination were found to have poor hygiene and 23% of the subjects reported that they needed dental care (Cumella, S., Ransford, N., Lyons, J., & Burnham, H., 2000).

Beange et al. found that the most common medical problem among 202 adults with mental retardation living in both institutions and community settings was dental disorders, in 86% of the sample. Visual disturbances were next in frequency at 68% (Beange, H., McElduff, A., & Baker, W., 1995). Scott et al. conducted an oral health assessment of 101 adults with intellectual disabilities in Australia in 1991, comparing the results to that of the general population. They found higher rates of dental visits in the previous 12 months and lower rates of plaque and cavities, but higher rates of severe periodontal disease, oral pathology, and tooth misalignment. The examination revealed that while 90% required dental treatment at the time of the study, only 42% felt that they needed treatment (Scott, A., March, L., & Stokes, M. L., 1998).

2.2.2.3 Nutrition and Lifestyle

Smoking prevalence rates for adults with mental retardation vary. Tracy and Hosken found a smoking prevalence rate of 36% in adults with intellectual disability in Australia compared to 26% in the general population (Tracy, J. & Hosken, R., 1997). Robertson et al. found lower smoking prevalence in a study of 500 adults with intellectual disabilities in England than in the general population. Smoking prevalence varied according to residence, with those in more restrictive settings having lower prevalence rates of 2% compared to 12% in the least restrictive setting. Additional findings were a high prevalence of poor diet, obesity in females, and lack of activity. Those with greater ability and in less restrictive residential settings had higher rates of smoking and obesity. There were high rates of inactivity (84% of men and 88% of women) and those with lower ability and in more restrictive settings had higher rates of inactivity (Robertson, J. et al., 2000). O’Brien, Tate and Zaharia found that tobacco use was significantly related to IQ, with those with higher IQ’s exhibiting higher tobacco use (O'Brien, K. F., Tate, K., & Zaharia, E. S., 1991).

Fujiura et al. used survey research and clinical record reviews to study 49 individuals with intellectual disability and Down Syndrome living with their families and using one specialty clinic in Chicago. The purpose of the study was to explore the relationship between diet, exercise, disease status and degree of social integration. They found that 30% of females and 25% of males were obese, and the most important predictors were access to recreation and social opportunities and not diet, physical status and activity. They conclude that the field of mental retardation focuses excessively on the study of medical and secondary conditions to the exclusion of developing an understanding of health promotion opportunities and techniques and exploring environmental variables in health status research with this population (Fujiura, G. T., Fitzsimons, N., Marks, B., & Chicoine, B., 1997).

Rimmer et al. found a higher prevalence of obesity among 364 adults with mental retardation living in various residential settings in a large Midwestern state. The prevalence rate was 59% for females and 27% for males, with less obesity among those with more severe intellectual impairments. Those living with their families had higher rates of obesity than those living in congregate settings, including group homes, ICF's/MR or institutions. They concluded that less restrictive and unstructured settings probably increased access to food and decreased access to structured activity, and recommended further research, close monitoring of body weight and fat, and providing instruction to parents in weight control (Rimmer, J. H., Braddock, D., & Fujiura, G., 1993). In a later study, Rimmer et al. examined 129 adults with mental retardation living in institutions, group homes, or families. They found that those in institutions had lower BMI and body weights than those in either group homes or family settings, while those in the group homes had higher rates of smoking, alcohol and coffee use, and exercised less than those in either the institution or family settings. They concluded that health promotion initiatives should be directed to those living in less restrictive settings of group homes, supported living and family homes (Rimmer, J. H., Braddock, D., & Marks, B., 1995).

Rubin et al. found similar results in a retrospective record review of 283 adults with Down Syndrome in a large specialty clinic. Forty-five percent of men and 56% of women were overweight, with those living in a family setting having a higher prevalence of overweight than those in group homes (Rubin, S. S., Rimmer, J. H., Chicoine, B., Braddock, D., & McGuire, D. E., 1998). Braunschweig et al. assessed 48 adults with Down Syndrome living in the Chicago area and found extremely high prevalence of overweight, large waist circumference, low intake of fruits and vegetables, and lipid levels within the normal range (Braunschweig, C. L. et al., 2004).

Limited research has been conducted related to drug and alcohol use and abuse but in general, the prevalence of drug and alcohol use is lower in those with mental retardation than in the general population (Edgerton, R. B., 1986). Users tend to have higher IQ's than non-users, and those who abuse these substances experience significant life consequences, such as difficulties at home or work (McGillicuddy, N. B., 2006). One study of 122 adults with mental retardation found the prevalence of alcohol users was 39%, with 4% using illegal drugs, but the proportion of those classified as abusers was roughly equivalent to those who were non-abusers. The authors concluded that while the prevalence of substance abuse users is lower than in the general population, the potential for misuse is greater, due to cognitive and other skill deficits (McGillicuddy, N. B. & Blane, H. T., 1999).

2.2.2.4 Mental Health

Mental illness is difficult to diagnose in individuals with mental retardation. Prevalence estimates vary widely, with projections ranging from ten to forty percent (Borthwick-Duffy, S. A., 1994; Reiss, S, Goldberg, B, & Ryan, R., 1993), but the overall consensus is that the prevalence for some conditions is higher than in the general population. The variance in prevalence estimates is due to problems with definitions, problems of identification, and deficiencies in research methodology (Borthwick-Duffy, S. A., 1994; Kerker, B. D., Owens, P. L., Zigler, E., & Horwitz, S. M., 2004). The concept of diagnostic overshadowing, developed by Ohio State professor Dr. Steven Reiss (Nisonger Center for Mental Retardation and Developmental Disabilities (MR/DD), 2004), describes the tendency for mental illness to be under-diagnosed in individuals with mental retardation due to an assumption that negative behavior results from the cognitive deficit and not an underlying mental illness (Reiss, S., Levitan, G. W., & Szyszko, J., 1982). The presence of mental illness in individuals with mental retardation can complicate efforts to diagnose and treat physical health problems (Minihan, P. M. & Dean, D. H., 1990; Minihan, P. M., Dean, D. H., & Lyons, C. M., 1993; Minihan, P. M., Dean, D. H., & Lyons, C. M., 1993) and the medications used to treat mental illness can have a negative impact on physical health (National Association of State Mental Health Program Directors, 2001; Reiss, S. & Aman, M. G., 1997).

2.2.2.5 Dementia

Researchers have found high rates of dementia associated with Alzheimer's (DAT) in individuals with Down Syndrome. Janicki and Dalton found that 60% of adults age 60 and above with Down Syndrome had Alzheimer's compared to about 5 – 10% in the general population (Janicki, M. P. & Dalton, A. J., 2000). They also found that individuals with mental retardation but without Down Syndrome had similar prevalence of Alzheimer's as the general population. Zigman, et al., found similar results, concluding that rates of dementia in adults with mental retardation without Down Syndrome were equivalent to that of the general population (Zigman, W. B. et al., 2004).

2.2.2.6 Osteoporosis

Center et al. explored the prevalence of, and risk factors for, osteoporosis in 94 adults with intellectual disability in Australia. They found lower bone density in the group than in a comparable population matched for age. Risk factors were small body size, hypogonadism, Down Syndrome, physical inactivity and high phosphate levels in females. Low vitamin D levels and a history of fractures were common (Center, J., Beange, H., & McElduff, A., 1998).

2.2.2.7 Injuries

Injuries in people with mental retardation are noted in the literature primarily in conjunction with seizure disorders (Morgan, C. L., Baxter, H., & Kerr, M. P., 2003; Hsieh, K., Heller, T., & Miller, A. B., 2001) or self-injurious behaviors (McClintock, K., Hall, S., & Oliver, C., 2003; Nottestad, J. A. & Linaker, O. M., 2001), and research has a heavy focus on injuries in children with mental retardation (Sherrard, J., Tonge, B. J., & Ozanne-Smith, J., 2001; Sherrard, J., Ozanne-Smith, J., & Staines, C., 2004) . One study found significantly increased risk of injury related mortality and morbidity in a population of people with mental retardation aged 5 – 29 in Austrailia. Excess mortality was associated with asphyxia and drowning, and morbidity was associated with a higher risk of aspiration and falls. (Sherrard, J., Tonge, B. J., & Ozanne-Smith, J., 2001). Hsieh et al. studied 331 residents with developmental disabilities living in nursing homes in the Chicago area between 1989 and 1992, finding that 11% had injuries, with most caused by falls, followed by attacks by other residents and wheelchair accidents. Individuals who were ambulatory, used anti-psychotic drugs and had higher levels of adaptive behavior had higher injury rates (Hsieh, K., Heller, T., & Miller, A. B., 2001).

2.2.3 Summary

Adults with mental retardation have increased mortality and increased prevalence of certain diseases, with those with Down Syndrome frequently having the highest risk. Some studies have found high rates of untreated diseases and previously undiagnosed chronic conditions. There is some evidence that the presence of lifestyle related disease risk factors, such as smoking and obesity, is directly related to increased independence. Health promotion programs, particularly directed toward those living on their own or with family caregivers, are recommended by several authors (Rimmer, J. H., Braddock, D., & Marks, B., 1995; Fujiura, G. T., Fitzsimons, N., Marks, B., & Chicoine, B., 1997). The use of health assessment instruments can educate family caregivers to the health issues of their family members, potentially targeting the increased risks that appear to be related to greater independence.

2.2.4 Health Assessment

2.2.4.1 Background

Organized health assessment efforts began in the United States during World War II, when the American military began to conduct physical and psychiatric assessments to screen and select only those capable of withstanding the pressures of active duty, and also to reduce United States government liability for war-related disability compensation. A 23-question psychiatric screening test was developed and adopted in 1944, although the Army admits that its effectiveness was limited (Coates, Colonel John Boyd ed., 1955).

When the World Health Organization was formed in the late 1940's, it adopted a definition of health that has formed the basis for much of the health promotion and assessment activities that were to follow, although not without controversy (Chang, W. C., 2002; Callahan, D., 1973; Saracci, R., 1997). The definition was included among a statement of principles in its original constitution, signed July 22, 1946 (World Health Organization, 1948), including:

- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
- The achievement of any State in the promotion and protection of health is of value to all.
- The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.
- Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.

Health risk appraisals were advanced in the 1950's and 1960's by Lewis C. Robbins, M. D, Chief of Cancer Control with the US Public Health Service, John Hanlon, M.D., of Temple University, and Joseph Sadusk Jr, M.D., of George Washington University, and Jack Hall, MD, culminating in the publication of the 1970 Robbins and Hall book "How to Practice Prospective Medicine" (Wetzler, H., 1999; Hyner, Gerald C., 2000). A number of generic health risk appraisal instruments were released in the 1970's and early 1980's, including the Quality of Well Being Scale, the Sickness Impact Profile, and the McMaster Health Index Questionnaire, the Duke Health Profile, and the Nottingham Health Profile (McHorney, C. A., 1999).

The RAND Health Insurance Experiment was a 15-year study commissioned by the Office of Economic Opportunity and later taken over by the United States Department of Health, Education and Welfare (HEW), now the Department of Health and Human Services (HHS). Originally conceived as an experiment to gather data on health care utilization and insurance, which it accomplished, it also provided documentation of the value of self-administered health status surveys (Berkowitz, Edward, 2006; Stewart, Anita L & Ware, John E., 1992). Another RAND project, the Medical Outcomes Study, resulted in the creation of a survey instrument, the widely used SF-36, to measure health status (Ware, J. E., Jr. & Sherbourne, C. D., 1992). In an interview with Edward Berkowitz, Ph.D., of the National Library of Medicine, Kathleen Lohr, PhD, a RAND researcher at the time, states "…the common era of measuring health status and quality of life in effect can be traced to the Health Insurance Experiment and the set of people who developed the original questionnaires for measuring health status" (Berkowitz, Edward, 2006).

In subsequent years, health risk appraisal and health assessment instruments were widely adopted in the workplace and with at-risk populations by managed care organizations and other insurance plans. Internet-based health risk surveys are common, and there is some evidence pointing to equal effectiveness of web-based tools compared to traditional instruments (Bayliss, M. S. et al., 2003; Athale, N., Sturley, A., Skoczen, S., Kavanaugh, A., & Lenert, L., 2004; Ritter, P., Lorig, K., Laurent, D., & Matthews, K., 2004).

Health assessment also continues to be a priority of HHS, evident in another RAND study that it funded between 1998 and 2003. The study was designed to evaluate the potential for health risk appraisals in the Medicare population, including effectiveness, key features, beneficial effects, value of various types of follow-up, cost-effectiveness, and application to various sub-populations, technology and confidentiality. The findings, published in the report entitled "Health Risk Appraisals and Medicare," included evidence of some benefit of health risk appraisal when it was combined with follow-up intervention. Evidence of cost effectiveness and of benefits in vulnerable sub-populations was limited. The study recommended a pilot test in the Medicare program to determine the effectiveness of health risk appraisal (RAND, 2003). On

August 23, 2006, notice was posted in the Federal Register announcing a senior risk reduction demonstration project, with the goal of determining if "…risk reduction programs…that have been developed and tested in the private sector can also be tailored to, and work well with, Medicare beneficiaries to improve their health and reduce avoidable health care utilization" (Centers for Medicare and Medicaid Services, 2006).

2.2.4.2 Definitions and Classifications

The measurement of health can take many forms, all of which fall under the general heading of health assessment. The Society of Prospective Medicine defines health assessment as "any method that accesses and analyzes data about a person's or a population's health…" using data "…collected by questionnaire, observation, clinical/laboratory testing, medical records review, or from cost and utilization data" (Society of Prospective Medicine, 1999). Applications of health assessment include descriptive research, clinical trials, health policy, planning and program evaluation, resource allocation, population surveys and clinical practice (McHorney, C. A., 1999).

There are several ways to classify health assessment approaches. According to McDowell and Newell, classification schemes for health measurements can be functional, descriptive or methodological (McDowell, Ian & Newell, Claire, 1987). Functional classifications are based on the purpose of the instrument, descriptive are based on the content of the instrument and methodological are based on the type of instrument and techniques for administration.

A *functional classification* might distinguish, for example, between health risk appraisal (HRA) and health status assessment (HSA). Traditional health risk appraisals measure the impact of risk factors on health outcomes and compute the risk a person faces due to a variety of biological, lifestyle and hereditary factors along with the risk reduction that would result from altering any of the factors. They have as their basis mortality and morbidity figures and generally have three components: a questionnaire, a risk calculation, and educational materials targeting the identified health risks (Alexander, G., 1999). The primary goal of health risk appraisal is to prevent premature mortality (Wetzler, H., 1999).

Health status assessment differs in that the primary purpose is to measure the health and/or functioning of an individual or a population and not the risk of death. The Society of Prospective Medicine defines a health status index (assessment) as “a set of measurements designed to detect short-term fluctuations in the health of members of a population…” including “…physical function, emotional well-being, activities of daily living, and subjective feelings.” (Society of Prospective Medicine, 1999).

A *descriptive classification* might delineative between generic and disease specific instruments. Generic health assessment instruments measure a broad range of health related areas in the same instrument, such as physiological characteristics, functioning, and emotional well-being. Examples are the SF-36 (Ware, J. E., Jr. & Sherbourne, C. D., 1992) and the Duke Health Profile (Parkerson, G. R., Jr. et al., 1981). Disease-specific instruments are designed to gather in-depth individual information related to one particular disease or condition, such as asthma, diabetes, or cancer. Examples include the Arthritis Impact Measurement Scales (Meenan, R. F., Mason, J. H., Anderson, J. J., Guccione, A. A., & Kazis, L. E., 1992), and The Cornell-Brown Scale for Quality of Life in Dementia (Ready, R. E., Ott, B. R., Grace, J., & Fernandez, I., 2002).

A *methodological classification* includes things like self-administration vs. expert-administration, or the distinction between instruments that result in a single score vs. those that produce a profile (McDowell, Ian & Newell, Claire, 1987).

While numerous health assessment instruments exist for both the general population and for individuals with specific diseases, few are applicable to adults with mental retardation, Those that are available for this population were designed for clinical or professional administration, are psychometrically weak or untested, or are otherwise unsuitable for the current project. Chapter 5 provides a summary of the primary health assessment instruments used with adults with mental retardation.

2.3 CONCEPTUAL FRAMEWORK

The conceptual framework underlying the International Classification of Functioning, Disability and Health (ICF) will guide the development of this instrument. The ICF, developed by the World Health Organization, was released in 2001 following nearly a decade-long multi-national effort to improve its predecessor, the ICIDH, or the International Classification of Impairments, Disabilities and Handicaps.

The primary impetus for modification of the ICIDH was the evolving theoretical foundation underlying the concept of disability, which was shifting from a medical to a social/ecological model. The medical model views disability as a function of an individual with an inherent weakness or flaw requiring medical treatment or intervention. The desired outcome is successful treatment or care. The social/ecological model of disability, on the other hand, considers the impact of neighborhood, community, and environment as enabling factors in disability. Interventions include those addressing the needs of the individual, but also those that address his/her environment, social/public policies and legislation. In the social model, disability is more of a social *consequence* than the outcome of some limitation of the individual. While the medical model of disability focuses on impairment resulting from a disability, with the desired outcome of treatment or care, the social model focuses on barriers to the individual achieving their goals, in spite of that disability (Zarb, G, 1995), with the desired outcome of full social inclusion.

The ICIDH characterized the consequences of disease as a linear progression from impairment to disability and handicap, with impairment defined in terms of a loss of structure or functioning, disability as an inability to perform an activity within the normal range and handicap as a disadvantage resulting from a disability that prevented fulfillment of a social role. The ICIDH can be visualized in the following diagram:

Impairment → Disability → Handicap

Figure 1: Graphical Representation of the ICIDH

Release of the ICIDH in 1980 coincided with a period of rapid growth, visibility and power of the disability rights movement. It was not long before disability advocates sought revisions, but they were joined by researchers who also found fault with it. Concerns included the lack of recognition of the social and environmental influences on disability, with a resulting sense of blame for the individual with a disability (Hurst, R., 2003), and a lack of clarity in the definitions of handicap and disability (Pope, Andrew M & Tarlov, Alvin R., 1991).

The ICF represented a compromise between the two models, using the biopsychosocial model of health and functioning (Ustun, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M., 2003) to reconcile the need to incorporate both physiology and environment into the new framework. The ICF combines the biological elements of the ICIDH with the personal and societal environmental influences from the social model. It views disability as an outcome resulting from the interaction of an individual with his/her environment, and not as a characteristic of an individual resulting from a limitation in that individual. This approach is consistent with the findings of the Institute of Medicine, which in 2000 published a report documenting the emergence of an ecological model in the study of health and health behavior. In this report, the authors documented the emerging consensus that health promotion efforts should target the environmental and societal influences on health and not only the individual factors. Health interventions were categorized into one of three groups, those targeting individual factors with 'downstream' interventions, population or 'mainstream' interventions, and 'upstream' societal level public policy interventions (Smedley, B. D. & Syme, S. L., 2001).

The ICF is designed as a classification system for understanding health and disability and facilitating cross-cultural data collection, but the underlying conceptual framework has broad application to conditions and applications beyond that of disability measurement (Schneidert, M., Hurst, R., Miller, J., & Ustun, B., 2003; WHO, 2004; Bornman, J., 2004; Bickenbach, J. E., Chatterji, S., Badley, E. M., & Ustun, T. B., 1999), including use as a framework for the development of health assessment instruments (Kennedy, C., 2003; Bilbao, A. et al., 2003), and in the study of secondary conditions in individuals with disabilities (Simeonsson, R. J., McMillen, J. S., & Huntington, G. S., 2002). Its aims are to establish a basis for studying health and health outcomes, to establish a common international language for describing and analyzing health across countries and disciplines, and to provide a health outcome coding mechanism. Anticipated uses include data collection, health or quality of life research, clinical assessment, social policy development, and education (WHO, 2004). The ICF is represented graphically in figure 2.

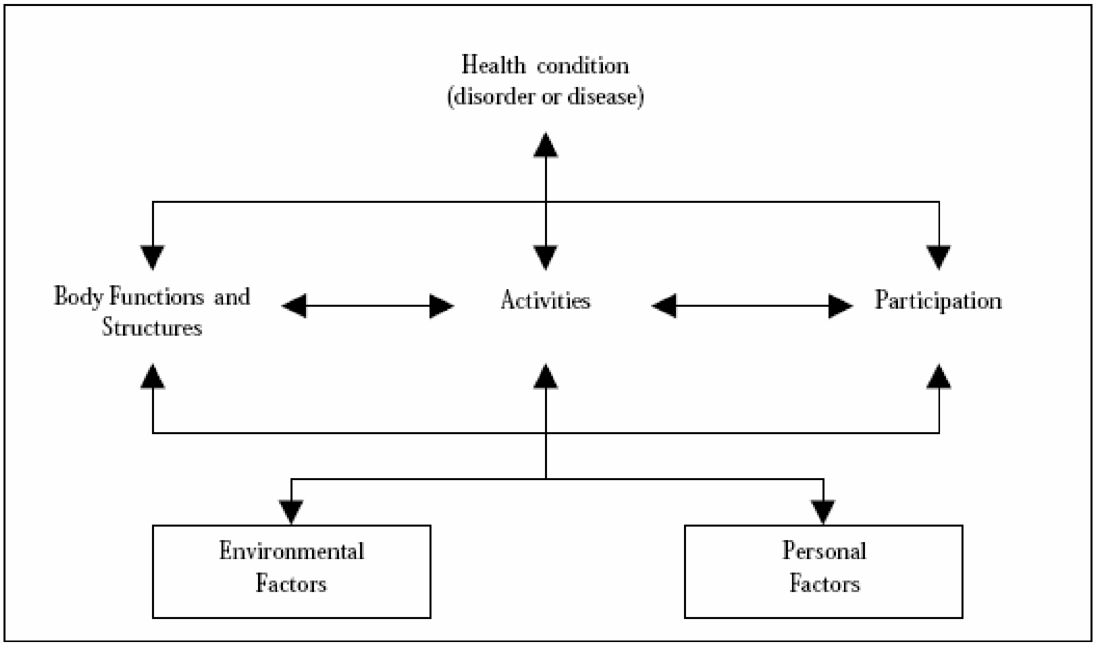


Figure 2: Graphical Representation of the ICF (WHO, 2004)

As illustrated in this diagram, the ICF uses a non-linear, multi-directional framework to classify health and health outcomes. Health is a function of the complex interaction of physiology (body functions and structures), individual activities (execution) and participation (involvement), influenced by environmental and personal factors. The middle row, body functions/structures, activities and participation, represents the ‘functioning and disability factor,’ and the lower row, environment and personal factors, represents ‘contextual factors.’ Health outcomes, therefore, result from the interaction of function and disability with the contextual factors of environment and individual characteristics.

This framework has relevance for the development of health assessment instruments. For example, one health outcome for an older adult with mental retardation and paraplegia may result from the interaction of the conditions themselves (body function and structure) with activity limitations (unable to walk and/or transfer) and participation (unable to perform self-care due to activity limitations), influenced by environment (lack of transfer equipment) and personal factors (advanced age).

Another example looks at the health outcomes for someone with mental retardation, cerebral palsy and mouth pain which may be partially explained by the interaction of gum disease (body function/structure) with an inability to grip an object (activity), a lack of tooth brushing and flossing (participation), a lack of access to dental care through the Medicaid system (environment) and a fear of dental services requiring sedation (personal). A health assessment instrument can capture, and a comprehensive health promotion strategy should target, each of these elements.

3.0 METHODOLOGY

3.1 STUDY PURPOSE AND OVERVIEW

The purpose of this study was to develop a new self-administered instrument for families to assess the health of adults with mental retardation who live with them. The study utilized the qualitative techniques of focus groups and individual interviews, combined with an in-depth literature review and expert interviews, to develop a draft of the instrument, which is to be presented to OMR for further modification and testing. The instrument was designed for proxy reporting by family members of adults with mental retardation. The instrument will complement OMR's existing health risk assessment used to evaluate the health of adults living in state funded residential facilities and potentially provide OMR with a mechanism to gather population statistics for those who do not live in such facilities.

3.2 DEFINITIONS

Adult: For the purpose of this study, adult will be defined as an individual at least 18 years of age.

HCQU: Health Care Quality Units. Groups of health care and management professionals who help county mental retardation programs monitor and improve the overall health status of individuals with mental retardation. (Office of Mental Retardation, 2004)

Health: a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization, 1948).

Mental Retardation: Significant sub-average intellectual functioning combined with significant adaptive functioning deficits in two skill areas with an onset before the age of 21.

OMR (Office of Mental Retardation): A department within the Commonwealth of Pennsylvania, Department of Public Welfare charged with oversight of services in support of individuals with mental retardation.

People-First Language: Communicating about individuals with disabilities in a way that presents them as people first, not defined by having a disability. Example: Individuals with mental retardation as opposed to 'the mentally retarded.' (Institute on Disabilities, 2004)

Pretest: Field testing of a draft health assessment instrument by gathering data on survey characteristics including question content, response options, length, type of administration, and other factors. Performed to obtain feedback and suggested improvements from potential users and experts in advance of formal pilot testing for reliability or validity.

Proxy Reporting: An individual completes the health assessment instrument in place of the individual who is the subject of the instrument. For the purpose of this study, the family caregiver is the proxy reporter for the health of their adult family member who resides with them. The proxy reporter can be a parent, a grandparent, a sibling, or an extended family member.

Residential Services: Formal supports provided to an individual with mental retardation in a group living arrangement (group home, supervised apartment, intermediate care facility for the mentally retarded – ICF/MR). In this study, and the instrument under development, these individuals are excluded.

Supports Coordinator: The name for case managers operating in Pennsylvania's mental retardation system. Supports coordinators help individuals and families to plan, locate, coordinate and monitor supports and services, and inform them of, and help them to exercise, their rights. (Office of Mental Retardation, 2004)

3.3 PARAMETERS

The instrument was designed in accordance with the following parameters, which were developed based on preliminary discussions with the OMR Medical director and overview of the health assessment literature:

1. The instrument will be designed for completion by family members of adults with mental retardation who are not receiving residential services.
2. The instrument will be as brief as possible and will be written in non-technical language at the lowest reading grade level possible.
3. The final instrument will be designed primarily for completion by families, but can also be used by mental retardation and health care professionals.
4. The instrument will include domains identified as a result of interviews, focus groups, and a literature review.

5. Medical records will not be necessary for completion of the instrument.
6. People-first language will be used in the instrument.

3.4 STAGES

3.4.1 Overview

This study began with exploratory research designed to gather instrument content, then proceeded to instrument development, a pretest, instrument modification, and finally, presentation of the instrument to OMR with recommendations for further testing. This process is illustrated in Figure 3.

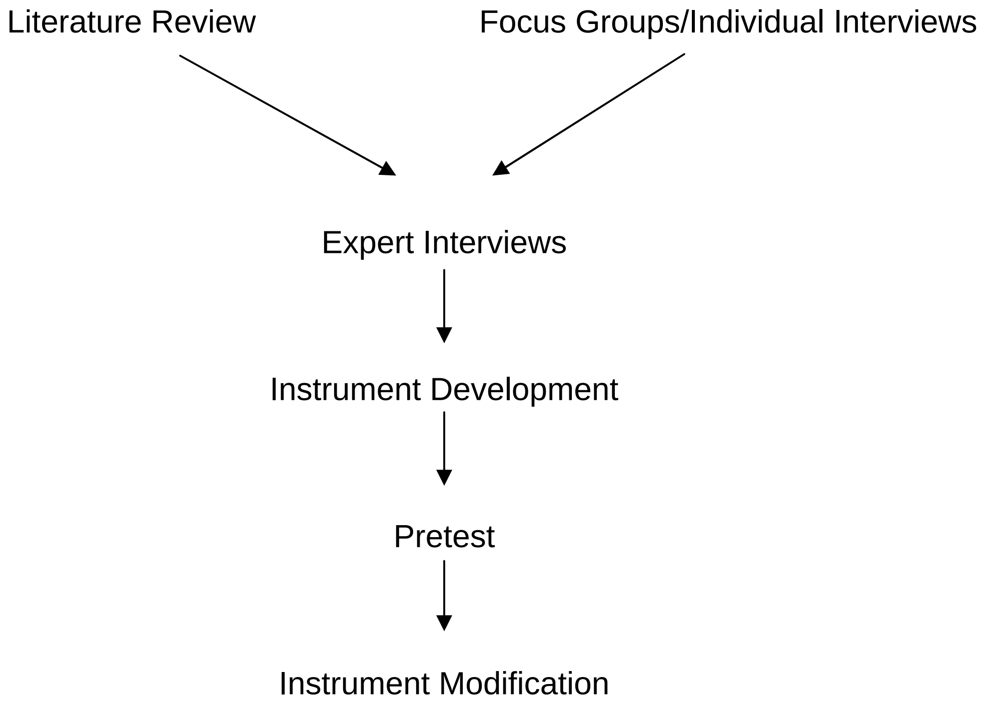


Figure 3: Stages of Instrument Development

3.4.2 Stage One: Development of Content

The first stage in this study was the development of the instrument content. This stage included several steps, including a literature review, focus groups and individual interviews for the purpose of developing a pilot instrument with content validity. These qualitative techniques are commonly used for the purpose of health assessment instrument development (Aday, Lu Ann, 1989; Aday, Lu Ann, 1989; McDowell, Ian & Newell, Claire, 1987; Wackerbarth, S. B., Streams, M. E., & Smith, M. K., 2002; McHorney, C. A., 1999).

3.4.2.1 Literature Review

An in-depth literature review was conducted to develop a comprehensive list of potential domains to include in the instrument. Specifically, the literature review sought to explore the health risk factors for adults with mental retardation and existing health assessment instruments that have been, or could be, used with this population. It should be noted that the literature review continued throughout the duration of the project to allow for incorporation of the results of newly published articles and, as a result, there were some minor modifications in the findings as the project progressed.

The literature related to health risk for adults with mental retardation was analyzed and summarized on a chart that collected the following information for each study:

1. Study Author
2. Population Description
3. Methodology
4. Limitations
5. Health Risks Factors Identified

6. Potential Domains

The grid was analyzed for trends, including the population types, the country of origin, the types of health risk factors identified, and the most common research methods used. A preliminary list of potential domains was then developed. Chapter 4 explains this process and the potential domains in greater detail.

A review of health assessment instruments, both in the field of mental retardation and for the general population, was conducted to determine what instruments are available that have been designed for, or used with, this or related populations, what health and health risk domains they measure, and how they have been tested for reliability and validity. A profile was developed for each instrument, including the following information, as available: Instrument, populations designed for/tested with, length (# questions, # pages, time to administer), mode of administration, use of proxy reporting, reliability and validity testing, and domains covered. Each instrument was evaluated for its potential use in this project, either in whole or in part. Instrument owners or developers were contacted as necessary for approval to use their instrument content in this study.

3.4.2.2 Focus Groups

Focus groups were conducted to gather family and individual input for incorporation into the instrument. This research topic is well suited to focus group research, as the literature on health concerns for people with mental retardation is not extensive and individuals with mental retardation and their families can be thought of both as marginalized groups and ones that have reason to be suspicious of traditional research methods. Focus group research has been found to be particularly appropriate in such situations (Kitzinger, J., 1999). Focus group research is also considered to be valuable for exploratory research (Basche, Charles E., 1987) and in the early phases of survey instrument development (Nassar-McMillan, S. C. & Borders, L. D., 2002; McHorney, C. A., 1999; Wackerbarth, S. B., Streams, M. E., & Smith, M. K., 2002; U.S.Census Bureau, 2003).

Subject Recruitment. Recruitment was initially conducted through a liaison at the state chapter of The Arc of Pennsylvania, an advocacy organization for individuals with mental retardation and their families with local chapters in many counties in the state. The Arc forwarded the IRB-approved materials (Appendix A), including a study description, to the local chapters, who in turn forwarded it to their parent/individual members either by email or by regular mail. The materials advised those who were interested to call The Arc to provide approval to be contacted. The Arc forwarded the contact information of all those interested to this researcher for follow-up.

Volunteers were grouped geographically by residence and those who were deemed to reside close enough to each other to travel to a group meeting were contacted, screened in accordance with the IRB-approved protocol (Appendix B), and their record was flagged to indicate if they were interested in attending a focus group meeting or participating in an individual interview. Potential volunteer information was entered by this researcher into a secure Microsoft Access database created to track participant data and findings. All focus group volunteers received a written summary of the study and a draft agenda along with the meeting date, time and location in advance of the meeting.

Recruitment was challenging, and with the exception of two clusters in western Pennsylvania, volunteers were spread out across the state. In addition, before the first focus group was held, the liaison at The Arc resigned, making additional recruitment using the original protocol difficult. As a result, the recruitment protocol was modified to include OMR as a source of participants, either directly or through an intermediary such as another organization or individual. For direct recruits, OMR was to forward the approved materials to the interested individual, who was to respond with an expression of interest in being contacted, and that information was forwarded to this researcher for follow-up. With intermediaries, OMR was to explain the study using the approved script, and solicit support to distribute the approved materials. The process from that point forward would be the same as with The Arc. Under this modified protocol The Arc, and in particular the local chapters that had been contacted by the state organization early in the recruitment process, could continue to forward interested volunteers as they were received.

Attempts were made to obtain focus group representation of the following groups, and recruitment continued until it was reasonably certain that no additional volunteers were immediately available: residence: rural and non-rural; race: Caucasian, African American, and Latino; family member level of mental retardation: mild, moderate and severe/profound; family member mobility: ambulatory and non-ambulatory; gender of family member: male and female; and gender of parent; male and female. The approved screening protocol included questions to identify these variables.

Moderation and Moderator Tasks. This researcher served as moderator for the focus groups, developed the outline of topics and questions, facilitated the interaction among group members, and encouraged discussion of emerging issues and participation among all members. All focus groups were opened by introducing the purpose of the group, describing how the interaction would proceed, reminding members that the meeting would be audio-taped, and obtaining written participant consent. Each group lasted for approximately ninety minutes.

Physical Setting and Psychological Climate. Focus group members were not compensated, but refreshments were available and meetings were held at times felt to be conducive to participation. Meeting locations were selected for the convenience of the participants and in settings that were comfortable and accessible. The room arrangements were established so that participants were facing each other with communication unimpeded. The groups were audio taped.

Focus group goals and questions were mailed to participants in advance of the meeting, along with a reminder about the meeting time and location (Appendix C), and reviewed at the start of each session. At the start of the session, the moderator explained the purpose of the group and the importance of the contribution they were making to the study and to the level of understanding of the issues. It was also made clear at the start of the sessions, and throughout as needed, that all contributions were valuable and there would be no negative consequences for sharing, or declining to share, with the group. Confidentiality of shared individually identifiable information was assured, and family member focus group participants were asked at the end of each group to sign a consent form if they were willing to participate in a pretest following development of the draft instrument.

Discussion Areas. The following questions were used as the starting point for facilitating the focus group discussions. The questions were designed to elicit the opinions of participants about their primary health concerns for their family member with mental retardation, and were based on preliminary discussions with the Medical director of OMR and the literature review on health and health assessment.

1. If you could change one thing about the health of, or the health care received by, your family member, what would it be?

2. What does ‘healthy’ mean for your family member? What does it ‘look’ like for him/her?
3. What concerns do you have about the health of your family member?
4. What keeps your family member from being healthier? What are the barriers?
5. (If Time Permits) What should an instrument measuring health look for?
6. (If Time Permits) What challenges did you face helping your family member to make the transition from pediatric to adult health care?

The following questions were used in the focus group for individuals with mental retardation. They were designed to identify the health issues of individuals with mental retardation and were based on preliminary discussions and the literature.

1. What do you think ‘health’ is??
2. Round Robin – Are you ‘healthy’?
3. Are you happy with your health?
4. What keeps you from being healthier?

Data Collection and Analysis. The moderator audio taped each focus group and prepared a full transcript afterwards. The moderator also took notes during the session, to highlight key points and to capture body language, observations, and other phenomenon that was not evident on an audio-tape. Each transcript was analyzed individually first, and then in combination with the other transcripts. Key ideas, words and phrases were highlighted, color-coded and re-arranged according to theme, first on paper and then electronically in Microsoft Word. The re-arranged text was then analyzed for any new constructs that might emerge. These procedures are consistent with established qualitative methods (Ulin, Priscilla R., Robinson, Elizabeth T., & Tolley, Elizabeth E., 2005; Pope, C., Ziebland, S., & Mays, N., 2000).

3.4.2.3 Individual Interviews

Individual interviews were originally intended only to supplement the focus groups if the characteristics of focus group participants were deemed too narrow to adequately represent a minimum range of characteristics and health needs. Due to the low level of participation in focus groups, the revised IRB-approved protocol was used to provide for an expanded role for interviews with all interested candidates, regardless of geography or demographic characteristics, being recruited for a phone interview.

All study participants living within the same region with at least 3 other volunteers were recruited for a focus group, but if they indicated during the screening telephone call that they were unavailable to attend a group meeting, the researcher presented the interview option. Therefore, some interview candidates were those who had earlier indicated that they could not attend a focus group, while other candidates were recruited following the focus groups, using the revised protocol, for the sole purpose of a telephone interview. Recruitment continued until it was felt that no additional volunteers could be obtained using the approved protocol.

All interview candidates were contacted initially for screening purposes and to set up the interview, held at the convenience of the volunteer. A letter of confirmation was mailed to participants in advance of the interview (Appendix D), summarizing the study and explaining what would take place during the interview, unless they already received the materials due to having expressed their intent to attend an earlier focus group meeting.

If individuals were not interested at the time of follow-up contact, the researcher attempted to determine the reason and documented that along with the individual characteristics, if the person was willing to provide that information or had already done so. An analysis was conducted to determine if there were any common characteristics among those who declined to be interviewed. Any potential impact on the findings was evaluated.

Individual interviews were semi-structured, conducted over the telephone, using the same questions as used in the focus groups (see Appendix C), but allowing participants or the researcher to take the conversation in a different direction if necessary (Britten, N., 1995). There was no compensation for volunteers. The length of the interview was approximately 60 minutes, with some shorter and some longer. All volunteers consented to being audio-taped. Detailed notes were taken during the interviews, and the tapes were re-played after each interview to fill in any gaps in the notes. A detailed report of each interview was prepared and data was entered into the Access database, which made it possible to analyze question results in various combinations, and calculate the number of times a particular issue was raised. This level of detail, and this type of analysis, was not possible with the focus group data as, due to the nature of the group conversations, it was frequently difficult to attribute a particular comment to one single person. The results of the interviews were analyzed for key themes and concepts. A detailed report was then prepared summarizing the results.

3.4.2.4 Expert Interviews

Expert interviews were conducted to obtain input on the concepts that evolved from the literature review, focus groups, and individual interviews. Specifically, the goal was to determine if the domains that had emerged were comprehensive, or if any key issues were missing, and to gather information related to health assessment and health assessment instruments with this population. Experts, identified in consultation with the Medical director of OMR and chosen for their knowledge of health issues for adults with mental retardation, were to include at a minimum, a parent, an advocate, and a physician. Experts were contacted by telephone to determine their interest, after which a face-to-face interview was set up at the convenience of the volunteer. A briefing paper was prepared for the experts, consolidating a summary of the results of the focus groups, individual interviews, and literature review, and providing a list of potential domains. Where the experts were not able to review the paper in advance, the expert was given the opportunity to provide comments at a later date, by email or in a follow-up interview. In all cases, the findings were reviewed at the beginning of the expert interview. Interview times ranged from 60 to 90 minutes, and were not taped. Extensive notes were taken, and a detailed report prepared immediately following each interview.

The experts chosen for this phase were asked the follow questions:

1. Are the themes that emerged from the focus groups and individual interviews comprehensive?
2. Are there any additional themes that should be included in the instrument?
3. Are you aware of existing health assessment instruments for adults with mental retardation, and do you have any knowledge of their potential utility in this population?

3.4.3 Stage Two: Development of Instrument

The results of the literature review, focus groups, and interviews were synthesized, and a master list of domains prepared. Content was then developed to address each of the identified domains. Existing instruments were examined to determine if questions had already been written to address the identified domains and the extent to which such content could be included in this instrument.

The instrument was written at the lowest reading level possible given the content, and using people-first language. The instrument was to be a self-administered paper instrument designed to be transmitted via postal service. OMR’s intent was to add a feedback mechanism that would provide users, upon return of a completed instrument, with a written summary of the identified health issues and recommended actions and resources for those conditions. Developing this mechanism, however, was outside the scope of this study.

3.4.4 Stage Three: Critique of Instrument

The pretest consisted of a number of steps, including expert (OMR) review of the draft instrument, modification, other expert review of the modified instrument, the caregiver completion of the draft instrument, analysis of the returned instruments, expert (OMR) review, and final modification. Expert review from OMR, which was provided by their Medical director, served several purposes, including clinical review of the questions and terminology and input into disease risk factors as addressed in the instrument. Other experts provided similar, although less clinical, written feedback.

Pretest participants were comprised of a sub-set of the focus group and interview participants, all of whom were asked early in the study if they were willing to complete the draft instrument and provide feedback to the researcher in a telephone interview. Four semi-structured interviews were conducted from among those who participated in focus groups and individual interviews. The fifth participant was unable to participate within the time frame allowed due to personal circumstances. A fifth semi-structured interview was conducted with the parent who had served as an expert. All interview subjects, except for the parent expert, were randomly selected from among those who indicated their willingness to participate in the pretest.

Pretest interview questions were developed based on the expert reviews of the draft instrument and an analysis of the returned surveys from pretest participants, along with the impressions of the researcher about questions that may have been considered confusing. All five pretest participants returned their completed surveys in self-addressed, stamped envelopes provided for this purpose, allowing for an analysis of errors and omissions. Questions that seemed to have created confusion, or where several participants missed a skip pattern or omitted a question entirely, were targeted for inclusion in the pretest questionnaire. Chapter 5 provides detailed information about the pretest results and the resulting instrument modifications.

3.4.5 Stage Four: Modification of Instrument

The pretest and expert review results were compiled in a chart that displayed, by question, individual and expert comments and errors/omissions, along with recommended changes. The results were analyzed and discussed with the OMR medical director, after which the instrument was modified and final formatting changes made. The instrument was converted from Microsoft Excel, where the draft was prepared, to Microsoft Word, for presentation to OMR.

3.5 HUMAN SUBJECTS

3.5.1 Confidentiality

Study participants included both individuals with mental retardation and parents of adults with mental retardation. Individuals were assured of the confidentiality of the individually identifiable information. Family members disclosed confidential information about their family member during this qualitative study. Confidentiality of shared individually identifiable information was assured during the family focus groups and individual interviews. All meeting transcripts and notes excluded such individual information and communications with study participants assured confidentiality. Focus group and interview summaries and transcripts were prepared without the inclusion of individually identifiable information. All materials which included individually identifiable information were maintained in a private, locked area.

3.5.2 Risks

There were no known risks to the individual with mental retardation or the family member by participating in this study, other than possible violation of confidentiality of individual health information during the focus groups, as noted earlier. The risk of potential violation of confidentiality was outweighed by the benefit to the participants in identifying potential areas of health risk that require attention. Participation in this study was voluntary. Initial communications reminded potential participants of that and of the fact that there would be no repercussions for either participation or failure to participate.

IRB approval for this qualitative study was obtained initially prior to implementation, and again when the protocol was revised.

4.0 FINDINGS

4.1.1 Group and Interview Participants

There were 28 total recruits for group and individual interviews (Table 1). Fourteen participants were recruited by The Arc, and the remaining participants were recruited by, or as a result of, OMR efforts. Of the 28 recruits, 6 did not participate. Two of the six could not be reached with the information provided by the recruiter. 4 were contacted but were unable to participate. Three of the four who did not participate indicated that it was due to scheduling difficulties, and one did not provide a reason. Of the 22 total participants, 12 attended one of three focus groups and the remaining 10 participated in individual interviews.

Table 1: Study Participants

Total Recruits	28
Focus Group Participants	12
Caregivers	7
Individuals	5
Interview Participants	10
Caregivers	10
Individuals	0
Non-Participants	6
Unable to Reach	2
Unable to Participate	4

One of the three focus groups included five individuals with mental retardation, and the remaining two groups participants included seven caregivers. The individual focus group was held in a private dining room at Hoss's Steak and Seahouse in Grove City, Pennsylvania. One of the caregiver focus groups was held in the library of Achieva, the southwest Pennsylvania chapter of The Arc. This focus group had 3 attendees. Another five were supposed to attend but did not due to schedule conflicts, and four of them later participated in telephone interviews. The other caregiver focus group was held in the home of one of the attendees in rural Mercer County.

Table 2: Characteristics of Participants

Characteristic	Focus Groups	Interviews	Combined
	Percentage and Count, by Type of Participation		
Region	% (n)	% (n)	% (n)
Northwest	75.0 (9)	10.0 (1)	45.5 (10)
Southwest	25.0 (3)	40.0 (4)	31.8 (7)
Central	0.0 (0)	30.0 (3)	13.6 (3)
Northeast	0.0 (0)	10.0 (1)	4.5 (1)
Southeast	0.0 (0)	10.0 (1)	4.5 (1)
Level of MR of Individual	% (n)	% (n)	% (n)
Mild	50.0 (6)	30.0 (3)	40.9 (9)
Moderate	33.3 (4)	40.0 (4)	36.4 (8)
Severe/Profound	16.6 (2)	20.0 (2)	18.1 (4)
Refused to provide	0.0 (0)	10.0 (1)	4.5 (1)
Gender of Participant	% (n)	% (n)	% (n)
Male	16.7 (2)	0.0 (0)	9.1 (2)
Female	83.3 (10)	100.0 (10)	90.9 (20)
Gender of Individual	% (n)	% (n)	% (n)
Male	50.0 (6)	60.0 (6)	54.5 (12)
Female	50.0 (6)	40.0 (4)	45.5 (10)

Table 2 (Continued)

Characteristic	Percentage and Count, by Type of Participation Focus Groups	Interviews	Combined
Residence	% (n)	% (n)	% (n)
Rural	75.0 (9)	20.0 (2)	50.0 (11)
Non-rural	25.0 (3)	80.0 (8)	50.0 (11)
Age of Caregiver Participant			
Mean	59.6	58.0	58.7
Median	60.0	55.0	58.0
Standard Deviation	6.2	8.1	7.2
Range	19.0	24.0	24.0
Range Values	49 - 68	49 - 73	49 – 73
Age of Individual Participant			
Mean	29.5	NA	29.5
Median	30.0	NA	30.0
Standard Deviation	7.1	NA	7.1
Range	14.0	NA	14.0
Range Values	22 - 36	NA	22 – 36
Age of Individual (cared for by Caregiver Participant)			
Mean	30.4	28.8	29.5
Median	26.0	23.0	25.5
Standard Deviation	14.2	11.3	12.3
Range	41.0	33.0	43.0
Range Values	20 - 61	18 - 51	18 – 61
Ambulatory Status	% (n)	% (n)	% (n)
Fully Ambulatory	83.3 (10)	100.0 (10)	90.9 (20)
Fully Non-ambulatory	8.3 (1)	0.0	4.5 (1)
Incomplete Response	8.3 (1)	0.0	4.5 (1)
Race	% (n)	% (n)	% (n)
Caucasian	100.0 (12)	90.0 (9)	95.5 (21)
African American	0.0 (0)	10.0 (1)	4.5 (1)
Hispanic	0.0 (0)	0.0 (0)	0.0 (0)
Other	0.0 (0)	0.0 (0)	0.0 (0)

Participants were representative of all regions of the state, but all of the focus groups took place in Western PA. Interviews were spread out across the state, with more in Southwest PA than in any other region, followed by Central PA. Northeast and Southeast PA had the smallest proportion of participants. About half of the participants identified themselves as coming from rural areas, and about half from non-rural areas. Most of the focus group participants identified themselves as living in rural areas, whereas most of the interviews participants identified themselves as living in non-rural areas.

All but two of the focus group participants, which included both caregivers and individuals with mental retardation, were female. Caregivers had a mean age of 58.7, with focus group participants slightly older. One interview participant declined to provide her age. Among the individuals who participated, the mean age was 29.5. One interview participant declined to provide her age.

All focus group participants were Caucasian, and only one of the interview participants was African American, for a total proportion of 95% Caucasian and 5% African American. These proportions differ from prevalence estimates of 71% of non-institutionalized adults with retardation being Caucasian, 22% African American, and 6% other (University of Minnesota, 2003). Attempts were made to recruit African American and Hispanic participants, but were not successful. A local chapter of The Arc in the Philadelphia area was contacted specifically for this purpose, and while their initial indications were that they would be able to assist in convening a group, that ultimately did not occur.

The individuals residing with, and cared for by, the caregiver participants had a mean age of 29.5, with slightly more males than females, 54% to 46%, consistent with epidemiological studies that have found the prevalence of retardation to be slightly higher in males than females

(University of Minnesota, 2003). Focus group caregivers had slightly older family members, 30 years of age compared to nearly 29. Most of them were fully ambulatory, with only one using a wheelchair all of the time. Individuals with mild mental retardation represented the largest proportion, with 41%, followed by moderate retardation at 36% and severe or profound at 18%. One caregiver declined to provide this information. This study, therefore, represents individuals with more severe levels of retardation than the general population, as most studies have shown that about 75% of all individuals with retardation have mild retardation (Murphy, C. C., Boyle, Coleen, Schendel, Diana., Decoufle, P., & Yeargin-Allsopp, M., 1998).

Total participation was lower than expected, but not uncommon for exploratory studies of this sort (Wackerbarth, S. B., Streams, M. E., & Smith, M. K., 2002). Several attempts were made to increase the number of participants, including modifying the protocol to add an additional recruitment method and expanding the interview component to attract volunteers who might not have been available otherwise. Recruitment was halted, and interviews ceased, only when it was felt that the revised protocol would not attract any additional volunteers. The initial protocol was approved by the IRB in the fall of 2004, the revised protocol in the summer of 2005, and the final telephone interview was conducted in the spring of 2006. Recruitment continued throughout this entire period.

4.1.2 Literature Review

An initial literature review was conducted to identify, generally, the health issues for adults with mental retardation. Those results are included in chapter 2. Much of the research in the area of health and mental retardation is based on case and prevalence studies. While those studies are of great importance, for the purpose of this project it was also important to attempt to identify the risk factors for various conditions and not just their prevalence. Therefore, a second literature review was conducted for the purpose of locating studies that are related specifically to the health risk factors for increased morbidity and mortality in adults with retardation.

MedLine, PsychInfo, and CINAHL were all searched using the following search terms (alone and in various combinations): mental retardation, cognitive disability, disability, intellectual disability, learning disability, health, risk, health risk, health assessment. Locating the literature was a challenge, due to the varied terminology used in describing mental retardation, and the fact that some mental retardation journals are considered to be within the realm of psychology or general academia, and not available remotely or on paper through the University of Pittsburgh health sciences library system.

Articles were screened as follows: Reports of primary research related to adults with mental retardation were maintained, and the following were excluded:

1. Descriptive or prevalence studies, unless such studies identified risk factors,
2. Research based exclusively in mental retardation institutional settings, as defined by the researcher,
3. Studies where risk factors were not identified, and
4. Studies where the methodology was weak or the results not clearly stated.

Initially, the intent was to examine only those studies with the greatest relevance for this project, specifically those conducted in the United States related to individuals who lived in family settings. Only a handful of articles met these criteria, therefore the scope was expanded. A total of 34 articles were maintained for further analysis. Appendix E provides a summary of each article, along with the identified risk factors and domains. While the focus in this step was on reviewing literature that identified specific risk factors for disease and increased mortality, other studies examining the prevalence of specific diseases were considered as necessary to assist in development of the instrument. Relevant findings from both literature reviews are integrated into the discussion of the results of the focus groups and interviews.

4.1.3 Expert Interviews

Following completion of the individual interviews, nine expert interviews were conducted with five people. The experts, identified in conjunction with the OMR medical director, consisted of:

- A parent and caregiver of an adult with mental retardation who is very active in her local community, with other parents, and on various advisory boards in the state.
- The executive director of The Arc
- The executive director of Philadelphia Coordinated Health Care (PCHC), a program designed to promote the health and well-being of individuals with mental retardation. Two interviews were conducted with this expert.
- The medical director of OMR. Three interviews were conducted with this expert.
- A Philadelphia-based physician with extensive experience in treating individuals with mental retardation of all ages, trying to promote health in this population, and attempting to enhance the responsiveness of the medical community to their needs. Two interviews were conducted with this expert.

Each expert was asked the same questions. First, after providing them with an overview of the findings, they were asked for their overall reaction. They were then asked if the list of potential domains was comprehensive or if anything was missing. Finally, they were asked if they had knowledge of any health assessment instruments that either have been used or may be helpful with this population. Immediately following each interview, a detailed summary was prepared. After the final interview, the results were analyzed for common themes and reactions.

4.1.4 Health Issues in the Context of the Conceptual Framework

The results from the four information sources – focus groups, individual interviews, literature review and experts -- will be considered in conjunction with conceptual framework of the ICF presented earlier, as it is this framework that governs the development of the instrument. In the ICF model, factors influencing health are divided into two components: those relating to the individual, including the body, activities, and involvement in various activities, and those that influence the body, meaning they are contextual in nature. Those two components are further divided, with the individual represented by body structures, functions, activities, and participation, and the contextual factors comprised of environmental and personal factors. Figure 4 displays the model in a grid format. The issues raised by the four sources are categorized according to the ICF domain(s) in which they best fit, and placed into the grid for further analysis. Issues raised by focus groups are preceded with the letter G, in interviews with the letter I, in the literature review by the letter L, and by the experts with the letter E.

All five ICF domains were noted by at least one source, and issues related to the body and functioning were raised the most often. This is largely because the literature review focused heavily on the physiological domains, and less on contextual factors. It should be noted that the literature review results displayed below include both the literature regarding risk factors and the results of prevalence studies, as appropriate.

<table>
<tr><td colspan="6">HEALTH CONDITION</td></tr>
<tr><td colspan="2">BODY FUNCTIONS/STRUCTURES

PHYSIOLOGICAL

I: ALLERGIES
I/L: CARDIOVASCULAR
L/E: DEMENTIA
I/G/L/E: DENTAL
I/G/L: DOWN SYNDROME
L: EPILEPSY
I/L: GASTROINTESTINAL
L: HEARING
L: LEVEL OF MR
I/G/L: MENTAL HEALTH
I/L: RESPIRATORY
I/L: SKIN
I/G/L: VISION
I/G/L/E: WEIGHT/BMI</td><td colspan="2">ACTIVITIES

TASK EXECUTION

L: FEEDING SKILLS
L: INDEPENDENCE IN DECISION MAKING
L: MOBILITY
L: SELF-HELP SKILLS</td><td colspan="2">PARTICIPATION

LIFE INVOLVEMENT

I/G: CUES
I/G/L/E: DENTAL
I/G/L: DIET
I/G/L: EXERCISE
I/L: HEALTH CARE UTILIZATION
L/E: INJURIES
L/E: MEDICATIONS
I/G/L: SOCIAL/RECREATIONAL
L/E: SUN EXPOSURE
L/E: TOBACCO USE</td></tr>
<tr><td colspan="3">ENVIRONMENT

EXTERNAL INFLUENCES

I/G/E: CARE COORDINATION
I/G/L/E: PROVIDER/HEALTH SYSTEM RELATED (INCLUDING DENTAL)
I/G/L: SOCIAL/RECREATIONAL</td><td colspan="3">PERSONAL FACTORS

INTERNAL INFLUENCES

L: AGE
L: GENDER
L: RACE</td></tr>
</table>

Figure 4: Results in the ICF

Table 3 displays the above results according to the source -- group, interview, literature or expert – and sorted by the number of sources that identified each issue.

Table 3: Domains Identified, ICF Domains, and Sources

			Source			
# Sources	Domain	ICF Domain	Interviews	Focus Groups	Literature Review	Expert Interviews
4	Dental	Body Function/Structures, Participation, and Environment	X	X	X	X
4	Provider/Health System Related (Barriers)	Environment	X	X	X	X
4	Weight/BMI	Body Function/Structures	X	X	X	X
3	Care Coordination	Environment	X	X		X
3	Diet	Participation	X	X	X	
3	Down Syndrome	Body Function/Structures	X	X	X	
3	Exercise	Participation	X	X	X	
3	Mental Health	Body Function/Structures	X	X	X	
3	Social/Recreational	Participation AND Environment (Barriers)	X	X	X	
3	Vision	Body Function/Structures	X	X	X	
2	Cardiovascular	Body Function/Structures	X		X	
2	Cues	Participation	X	X		
2	Dementia	Body Function/Structures			X	X
2	Gastrointestinal	Body Function/Structures	X		X	
2	Health Care Utilization	Participation	X		X	
2	Injuries	Participation			X	X
2	Medications	Participation			X	X

Table 3 (Continued)

			Source			
# Sources	Domain	ICF Domain	Interviews	Focus Groups	Literature Review	Expert Interviews
2	Respiratory	Body Function/Structures	X		X	
2	Skin	Body Function/Structures	X		X	
2	Sun Exposure	Participation			X	X
2	Tobacco Use	Participation			X	X
1	Age	Personal Factors			X	
1	Allergies	Body Function/Structures	X			
1	Epilepsy	Body Function/Structures			X	
1	Feeding Skills	Activities			X	
1	Gender	Personal Factors			X	
1	Hearing	Body Function/Structures			X	
1	Independence in Decision making	Activities			X	
1	Level of MR	Body Function/Structures			X	
1	Mobility	Activities			X	
1	Race	Personal Factors			X	
1	Self-help skills	Activities			X	

Individual interview participants were more willing to speak about the particular health conditions of their family member and spoke less about systemic concerns, while group participants focused more on issues that were *external* to the body. This can be partially explained by the anonymity that a telephone interview provides, and by focus group dynamics and peer pressure which can result in reluctance to speak about personal issues, and some participants being influenced by others. Neither venue provided content related to the skills/abilities of the individual (the activities ICF domain), or personal factors.

Experts noted health concerns that fell into the environmental, physiological/functioning, and participation domains. It is important to note here that individual participants, whether they participated by group or interview, were asked the same open-ended questions designed to elicit concerns for the health of their family member, and the literature review, on the other hand, focused on identifying the *risk factors* for disease in adults with mental retardation. The experts, however, were asked to review and comment on all three information sources. Different questions, therefore, guided each of the three methods, and could partially explain the disparity in the types of concerns identified by each method. Viewing the aggregate results within the framework of the ICF provides guidance in, and structure to, the development of the health assessment instrument.

4.1.5 Health Issues related to Physiology and Functioning

4.1.5.1 Physiological

The physiological domain in the ICF represents issues related to body structures, functions, and impairments. Of all issues raised by participants that fit into this domain, dental care and mental health issues were raised most frequently, although often in the context of lack of access and not related to the body itself. One participant expressed deep concern for the recurring depression experienced by her daughter and the lack of treatment options in her rural community. "I'm not giving her drugs just to knock her out," she stated, reporting that the medicines that she tried "…knocked her out cold." "She slept. She slept all day. I mean, she was a zombie. She slept all day, all night, round the clock."

The literature refers to the challenge of diagnosing mental illness in people with mental retardation (Reiss, S., Levitan, G. W., & Szyszko, J., 1982), and at least one study has found a high prevalence of un-diagnosed mental illness (Minihan, P. M. & Dean, D. H., 1990). The problem of dementia in those with mental retardation and Down Syndrome is another challenge, and was noted by one of the experts as deserving attention. Adults with Down Syndrome are at higher risk for early-onset Alzheimer's disease (Schupf, N. et al., 1998; Bush, A. & Beail, N., 2004).

Dental health was noted by all sources as problematic but, again, frequently related to access issues. One interview participant noted that she was very concerned about her 19 year old son with Down Syndrome, who had difficulty chewing following several dental surgeries. Another interview participant noted that when her dentist suggested extracting all of her 41 year old daughter's teeth because she has diabetes, she told the dentist. "… my husband has diabetes. I don't pull his teeth, so why would we pull her teeth?" At least one study has found poorer dental health for those living with their families (Lifshitz, H. & Merrick, J., 2003).

Level of mental retardation, presence of Down Syndrome, and BMI/obesity(Weight/BMI) are all health risk factors among those with mental retardation (Gabre, P., Martinsson, T., & Gahnberg, L., 2001; Janicki, M. P. & Dalton, A. J., 2000; Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W., 1999; Strauss, D. & Eyman, R. K., 1996; Beange, H., McElduff, A., & Baker, W., 1995; Janicki, M. P. et al., 2002; Gabre, P., Martinsson, T., & Gahnberg, L., 2001; Eyman, R. K., Call, T. L., & White, J. F., 1991; Patja, K., Molsa, P., & Iivanainen, M., 2001). Several participants expressed concern regarding the health problems associated with Down Syndrome, and all sources identified weight/BMI as a concern. *Vision* was an issue for several parents, one of whom expressed concern about the ability of visual assessment equipment to accurately test vision in people with Down Syndrome. The literature reveals that visual impairments can be under-diagnosed and often untreated (Beange, H., McElduff, A., & Baker, W., 1995), and that adults with Down Syndrome are at higher risk for visual problems like cataracts (Warburg, M, 2002)

Skin disorders were noted by one participant as being a great concern, and were found in one study (Janicki, M. P. et al., 2002) to be associated with lower intellectual functioning and in another to be frequently untreated (Beange, H., McElduff, A., & Baker, W., 1995). Respiratory-related mortality is related to lower intellectual functioning (Patja, K., Molsa, P., & Iivanainen, M., 2001), and was noted by one participant to be an area of concern. Hearing impairments are also a problem in Down Syndrome, and may be more prevalent in people with mental retardation (van Allen, M. I., Fung, J., & Jurenka, S. B., 1999; Beange, H., McElduff, A., & Baker, W., 1995). Presence of a seizure disorder is a risk factor for injury, hospitalization, and mortality (Morgan, C. L., Baxter, H., & Kerr, M. P., 2003).

Cardiovascular disease was noted as a concern by one participant. Elevated cholesterol is a risk factor for heart disease in the general population, and it has been found to be related to less restrictive settings and greater independence among those with mental retardation (Rimmer, J. H., Braddock, D., & Marks, B., 1995). The lifestyle choices that abound in more independent settings bring with them elevated risk resulting from the potential for making poor choices. Allergies and gastrointestinal disorders were noted as concerns by several participants.

4.1.5.2 Activity

The activity domain represents the abilities of the individual related to the bodily functions and structures. All risk factors falling in this domain were generated by the literature review. Impaired mobility, lack of self-help skills, and lack of feeding skills have been found to be related to increased morbidity and mortality in several studies (Eyman, R. K., Call, T. L., & White, J. F., 1991; Strauss, D., Kastner, T., & Shavelle, R., 1998; Tyler, C. V., Jr., Snyder, C.

W., & Zyzanski, S., 2000; Wilber, N. et al., 2002; Shavelle, R. & Strauss, D., 1999). Closely related, the concept of independence in decision making has been found to be directly related to smoking in adults with mental retardation (Tracy, J. & Hosken, R., 1997).

4.1.5.3 Participation

The domain of participation reflects the involvement of the individual with his/her environment, given physiology and ability. Parents consistently noted the need to watch for cues in the interaction of the individual with other people and in his/her environment. As many of their family members are unable to communicate that they are not feeling well, family members continually monitor them for signs of illness. This could mean a change in demeanor, eating habits, or routine, or the individual touching a part of his/her body. One mother of a 38 year old son with severe mental retardation relayed how she identified that her son was very sick by noticing that he seemed sad and refused to eat a Popsicle despite his usually voracious appetite. After watching him closely, she realized that something was very wrong and took him to the doctor, after which he was diagnosed with congestive heart failure.

The need to watch for cues to illness appeared to be related to fears about the well-being of their family member when they are no longer able to care for them. Some of the participants expressed great concern for what would happen if their family member had to go into a group home. One interview participant stated that she worries about whether group home staff would notice when something is wrong. “I’m his first line of defense,” she stated. And in the words of a focus group participant: “Do they know that that look means they are constipated? And that if they are acting a certain way, does that mean that they are having problems going to the bathroom, or you know, that because of the way they are acting you know that they don’t *feel* well and maybe they’ve got a fever.”

Limited participation in social activities was noted as a health concern by most participants and in the literature review related to its influence on overall well-being and obesity. The construct is divided here between the participation domain and the environmental domain, with the participation domain reflecting the actual socialization that the individual experiences, and the environment domain reflecting the social barriers in the person's environment. The literature has shown that socialization is inversely related to obesity in adults with Down Syndrome (Fujiura, G. T., Fitzsimons, N., Marks, B., & Chicoine, B., 1997; Ailey, S. H., Miller, A. M., Heller, T., & Smith, E. V., Jr., 2006).

One group participant explained that one of the best decisions she made for her 20 year old son with Down Syndrome was to use his SSI money to hire him a personal trainer at the local gym. "It has been one of the most wonderful things we have ever done…plus he goes to the gym and they have all, like, adopted him there, you know? All the guys. He goes to the weight room and he does his weights, and they do their weights. So there is like a little community of support there for him."

Health care utilization is included here as an indicator of potential increased morbidity and injury, related to physician, hospital and emergency room use, and also as an indicator of potential under-utilization of preventive services, including, for example, vision and hearing screenings, and breast and prostate cancer screenings (Minihan, P. M. & Dean, D. H., 1990; Davies, N. & Duff, M., 2001; Havercamp, S. M., Scandlin, D., & Roth, M., 2004). Several participants expressed concern over the lack of emphasis on preventive screenings for this population, and the inability of the health care system to make accommodations to get people the health care services they need. One mother of a 41 year old woman whose two aunts have breast cancer stated: "You know, I think that if you would take someone like '[name]' to a place you and I would go to, to get a mammogram, she would be put out of the place in two seconds because there would be no way they could examine her and no one would think about, well, its still important. This young woman has two aunts with breast cancer, she still needs to get that mammogram."

Improved diet and weight loss were issues for several participants. One parent indicated that she has to lock her freezer and keep very little in her refrigerator due to the excessive eating habits of her adult son. A participant in the individual group noted that she is aware of the foods that are healthy for her, but struggles with the desserts that she enjoys.

In the general population, poor diet and lack of exercise are related to obesity, which is a risk factor for increased morbidity and mortality. Several participants expressed the desire for their family member to exercise more. The literature in the area of mental retardation demonstrates increased prevalence of obesity and some nutritional deficiencies compared to the general population. One study of 48 adults with Down Syndrome in Chicago found that 89% were obese and none of the participants had adequate intake of fruits and vegetables (Braunschweig, C. L. et al., 2004). Insufficient intake of fruits and vegetables was also found in a study of 500 adults with mental retardation in the UK (Robertson, J. et al., 2000).

One expert noted that tobacco use is a concern for adults with mental retardation, and in particular those with mental illness. In the literature, findings with regard to the prevalence of tobacco use have been varied. Some studies have found similar rates of tobacco use compared to the general population (Havercamp, S. M., Scandlin, D., & Roth, M., 2004), some have found increased rates of tobacco use in adults with mental retardation (Tracy, J. & Hosken, R., 1997), and still others have found lower rates of tobacco use compared to the general population (Robertson, J. et al., 2000). Several studies have linked increased tobacco use to milder levels of mental retardation and presence of schizophrenia (Taylor, N. S., Standen, P. J., Cutajar, P., Fox, D., & Wilson, D. N., 2004; Hymowitz, N., Jaffe, F. E., Gupta, A., & Feuerman, M., 1997).

Sun exposure was noted briefly by one expert and is included due to its status as a risk factor for skin cancer in the general population. (Ivry, G. B., Ogle, C. A., & Shim, E. K., 2006; Han, J., Colditz, G. A., & Hunter, D. J., 2006).

One expert noted that polypharmacy and medication side effects are a concern in this population and deserve increased attention. Medications commonly prescribed for seizure disorders can have negative side effects (American Society of Consultant Pharmacists, 2006; Matson, J. L., Luke, M. A., & Mayville, S. B., 2004) particularly when used long term and when prescribed by multiple physicians.

Unintentional injuries and their risk factors have not been extensively explored in those with mental retardation. Some studies have found that those with greater mobility, seizure disorders, or feeding problems, and those taking anti-psychotic drugs are at higher risk of injury (Morgan, C. L., Baxter, H., & Kerr, M. P., 2003; Hsieh, K., Heller, T., & Miller, A. B., 2001; Sherrard, J., Ozanne-Smith, J., & Staines, C., 2004). It is reasonable to assume that injury risk for the general population extends also to those with mental retardation, although the extent to which this is true is not known. In this study, injury was noted by an expert as a concern, specific to equipment safety and aggressive behavior in the workplace.

4.1.6 Health Issues Related to Context

4.1.6.1 Environment

Contextual issues include the environment and personal influences not related to physiology, with environmental concerns raised more often by group and individual participants than concerns about the health of their family member. Participants reported concerns with care coordination received from ISCs and medical providers, and with barriers to accessing social and recreational opportunities. Participants also reported a variety of concerns about the health care system, including poor quality care, access barriers, and lack of respect for the individual and trust for the parent. While these issues are secondary to the health assessment approach, which focuses on identifying health issues that can be modified with medical intervention or education, they are consistent with the ICF model and are important to mention.

Barriers to Social and Recreational Opportunities. Several participants noted that their family members faced significant barriers in accessing social and recreational opportunities. One parent expressed that the lack of social opportunities contributes to her daughter's depression. "There is nothing here – we're parents…there is no social activity around here. I take her shopping, but that is shopping with Mom. That's not an interaction with other peers. If she is with her peers, she is fine. So we get back home and it's a day or two later we are back into our dull, humdrum lifestyle." Several parents pointed out that social opportunity becomes more challenging as their family member gets older. "You don't have people calling her up. We create her opportunities for her." Another parent reports that other parents are not aggressive enough about helping their family member to develop friendships. "People tend to be very over-protective and cautious….You don't have somebody you can call and say, hey, you want to come over and listen to my CD's?"

One participant from a rural area stated that, despite the lack of recreational opportunities, being in a rural area was helpful because people were supportive of each other. "In a rural community you don't get lost. You don't become a number. You know, people take you under their wing."

The literature supports the value of access to social and recreational opportunities in promoting health. Friendships and social opportunity were found to be better predictors of BMI than diet and activity level in a study of 48 adults with Down Syndrome (Fujiura, G. T., Fitzsimons, N., Marks, B., & Chicoine, B., 1997). In another study, access barriers, including high costs, transportation, lack of knowledge of where facilities were and lack of an exercise partner played a role in limiting exercise in adults with Down Syndrome (Heller, T., Hsieh, K., & Rimmer, J., 2002). Social isolation was linked to depression in a study of adults with Down Syndrome (Ailey, S. H., Miller, A. M., Heller, T., & Smith, E. V., Jr., 2006).

Provider, Health System, and Care Coordination Concerns. Concerns with providers and health systems, including care coordination, were raised by most participants. The concerns can be categorized as those related to quality, access or coordination. Quality issues were raised by a number of participants. One group participant is the parent of a 25 year old with profound mental retardation who has a tracheotomy and uses a feeding tube, and has a variety of complex medical conditions, including spastic quadriplegia, blindness, hydrocephalus, scoliosis, reflux, chronic lung disease, and a pediatric condition that was supposed to have resulted in her death before reaching adulthood. As a result, her mother has experienced dramatic challenges with regard to the health care system, while at the same time developing extensive knowledge of it. She relayed the following story: "…I really wish I could have confidence in everybody's knowledge of her condition and what to do about it…One time when she…got really, really, really sick, we went to [hospital name] in the middle of the night and after keeping us there for three or four hours they finally said, you know, I think she'd probably be safer at home. I think you should go home. [whispering] And she was so sick. It was really scary to go home. But we did. So they don't want her and they don't really know how to take care of her." In another situation, after her daughter pulled out her feeding tube, it took two days, two trips to the hospital, and tens of thousands of dollars in costs for the Medicaid program, including a stay in the ICU, because a physician put in the wrong tube.

Another group participant reported that she felt that her son received substandard care in a regional hospital. “When [name] had that jaw problem we took him down [to] the hospital in Pittsburgh. He had to have surgery…They weren’t going to let us spend the night. I told them [laughing], you’re going to have to pull me out of here. I stayed. At one point he was vomiting blood. And my husband was there too, and we were out hunting for help and we just couldn’t find it. You know, I mean he was just not being cared for. Again, second class, third class citizen.”

Several participants reported not receiving what would be considered standard treatment for someone without mental retardation. “I’ve gone through my life by me asking for tests and not vice versa” one person reported. Another reported that she had to ask the doctor to do a test that ultimately found a heart defect in her son with Down Syndrome, for whom heart defects are common. “I want my family member to get what I would be offered,” another stated.

Participants reported feeling like they and their family member were being treated with disrespect. Several reported feeling resentment at being told that their child should be institutionalized. “I took [name] to a doctor. And he said to lock him up. We would never do that. They said to take him down to Polk and lock him up. I just took [name] and we walked out.”

One participant reported that the doctor never speaks directly to her son, even though he can communicate well. Another participant, an individual with mental retardation, reported being very upset after she was given a gynecological examination by a male even though she had stated that she wanted one by a female. Another participant reported being discharged from a neurology practice after questioning the need for a seizure medicine when her family member was not diagnosed with a seizure disorder.

Access to health care providers was consistently problematic, regardless of rural/urban status. Participants reported having difficulty finding providers willing to take Medicaid, or to treat their family member due to their disabilities. “It took many calls and many visits to find just a primary care physician who was willing to become her primary care doctor”, reported one parent. The parent of several adults with mental retardation and complex medical needs reported great difficulty locating providers in her rural community, stating that she is bounced between physicians because they state that the issues are beyond the scope of their practice. “Physicians just kind of look at me and don’t know what to do.”

Participants reported long drive times and lengthy waiting times to see physicians who accepted Medicaid, and paying out of pocket for care when they could not locate a provider willing to do so. One parent reported paying out of pocket for dental care for this reason. Another parent reported that she drives almost an hour and a half each way to a dentist able to treat her son.

One individual with mental retardation reported that she lived with severe heartburn because she had to wait too long in the lobby to see the doctor. “So I just suffer. I take Tums and Rolaids…I get it so bad I can’t take it. I’m up half the night,” she stated. A parent reported that her son sees a chiropractor who works well with him but does not accept Medicaid. After her son lost his insurance through his parent’s employer, the chiropractor continued to treat him at no cost. “That bothers me, because I want to pay for services. I don’t want my son to be a charity case, but yet I appreciate this. We are very fortunate.”

Access to behavioral health care was also reported to be problematic, with medication frequently the only treatment made available to family members with mental retardation and mental illness. “There’s nothing a whole lot really available. You either go to a psychologist or someone where they want to put you on a drug, which isn’t really reaching a problem that you might have. There really aren’t that many counselors…”. One parent of a 34 year old daughter with mental retardation relayed a situation where the medications that were prescribed to treat her daughter’s depression resulted in excess sedation. “It did not solve her problem. It just merely put her to sleep.” She reported that, after she refused to continue to give the medications to her daughter, the behavioral health provider threatened to remove her daughter from her home. “I said you will have to find me first!” I’m not giving her drugs just to knock her out.” “I never had anyone say anything like that to me before, I was just totally floored. And I thought, I’m here for her benefit. I’m trying to do something to help her, and you’re threatening me? And I’m thinking, you’re the authority, you could do that!”

The expert interviews provided insight into the emphasis on provider issues in both the groups and interviews. The parent expert was not surprised, stating that she is very connected with other parents and they have reported similar experiences and opinions. She has experienced some of the provider concerns herself, related to both her son and her own health, and she feels that she has to be aggressive with providers to ensure that their needs are met.

Among the other experts, there was some surprise and disappointment with the focus on systemic issues. Several experts mentioned that the health care system has changed, and all people need to be more aggressive with their physicians in order to get their needs met. There was some thought, also, that parents of adults with mental retardation may, on the one hand, be reacting to the disrespect with which they have been treated by physicians but, on the other hand, may not treat physicians with the same respect that they demand from them.

The physician expert admitted that physicians don't necessarily "…come out of medical schools knowing how to work with people." He relayed a personal situation where he treated a young woman in a body brace by reaching underneath the brace the entire time, never thinking to ask her if she could remove it on her own. He stated that he has attempted to address the provider issues raised in this study by approaching medical schools to add content to their curriculums and the national board of examiners to add exam content, and by training providers directly. None of these approaches worked, in part due to crowded curriculums and testing protocols, and in part due to inability to recruit providers to training sessions.

Another, quite interesting, perspective on the excessive focus on provider issues was relayed by the physician expert, who thought that perhaps the negative reaction to the health care community was related to the general fear and apprehension toward the medical model of service delivery in mental retardation, which dominated the system for many years before parents and individual advocates began to demand change (Hurst, R., 2003; Carey, A. C., 2003; Ott, K., 2005). This expert also postulates that there may be an aversion to health promotion for this population for the same reason.

Another expert was not surprised with the focus on systemic issues, indicating that participants may have viewed the study as an opportunity to provide feedback to OMR on the issues of greatest concern to them. This expert also felt that OMR might benefit from hearing these family opinions, and stated that the results beg for more population-based research on the health issues of people with mental retardation, and the views of their families.

Care coordination was a significant concern, both relating to medical providers and, more frequently, mental retardation case managers (independent supports coordinators or ISC's). In general, participants felt that they were on their own in locating resources and coordinating between them. "…There is no good clearinghouse to get the help you need. You have to hunt down the help you need. There is no place you can go and say, here's my problem, who is good at dealing with this?" In the medical community, participants reported a lack of coordination, particularly in the transition from pediatric to adult medicine. "In pediatrics I had a real sense of a team and that there was coordination…and now it feels very fragmented," reported the parent of a daughter with complex medical needs. "Partially it was because those relationships have been built up over time. I … felt like the left hand knew what the right hand was doing. We've been able to find a pulmonologist [but] he has never spoken with the primary care physician. [There] isn't that sense of collective problem solving, you know?" Another participant reported that her daughter's doctors do not speak with each other, and the parents are expected to provide coordination between them.

Participants of both focus groups and interviews reported significant concern with the support that they receive from ISC's, stating that they are intrusive, do not provide assistance where it is needed, and cannot be relied upon. One parent reported her son is asked repeatedly by the ISC about his plans for leaving home. "…Every quarter when the caseworker has to meet with us, every time she will ask him if he has thought more about leaving home. She knows that this is not what we want at this point and she knows why. I consider that meddling. I don't appreciate it," she stated. "They meddle where they don't belong, but yet when it comes to coming up with the community resources, they haven't thought out of the box enough about what you could create." Another reported: "Oh my God, they change every three months. I mean, I don't even bother talking to them. It's like, pointless…I don't know what they are supposed to do."

Other participants report a lack of response from ISCs. One reported: "…We asked for a behavior plan...and we requested it through the base service unit – the county. I personally have gone to their office and requested the assessment to be done. And we were ignored. And we continue to be ignored." Another stated: "we have a caseworker and I don't get nothing done by her. She says she can't do nothing, she has to wait for her supervisor to do anything."

Several participants expressed that their family members receive less support from ISCs because they live at home. "When a child lives at home, they expect the parents to handle any and all problems. Because as far as the county is concerned, there are no problems. The problem only begins when your child goes into a residential setting. So I think children living at home never get the full benefit of county services at all because it is not a problem. We're low maintenance for caseworkers."

The parent expert concurred with group and interview comments about ISCs, stating that although she has a good one, she thinks it is only because she is very active and outspoken. She reports doing their work for them, including completing the state-required forms that the ISCs usually complete, and stated that she doesn't believe that she will get anything out of ISCs, so she never asks. "I learned not to believe professionals," she stated.

4.1.6.2 Personal Factors

Personal factors such as age, race and gender impact body structure and functioning, influencing health in a positive or negative way. Young and old age are both related to increased morbidity and mortality in those with mental retardation. Increased age was associated with increased likelihood of urinary incontinence, immobility, hearing impairment, and physical disorders in a study of 134 older adults with mental retardation (Cooper, S. A., 1998) and with increased rates of cardiovascular, digestive, musculoskeletal, sensory and respiratory diseases in a study of over 10,000 adults with mental retardation in New York state (Janicki, M. P. & Jacobson, John W, 1986). At the opposite spectrum, mortality was higher in people up to age 30 with mental retardation who also had severe or profound retardation (Patja, K., Molsa, P., & Iivanainen, M., 2001).

Research on gender differences in mental retardation is sparse and inconsistent (Umb-Carlsson, O. & Sonnander, K., 2006), and is included in this study primarily as a demographic variable necessary to evaluate gender-specific disease risk factors, such as breast or prostate cancer. Males have a higher prevalence of mental retardation (University of Minnesota, 2003), and were found to have a higher prevalence of respiratory disease in old age, while females with retardation have been found to have a higher prevalence of obesity (Rimmer, J. H., Braddock, D., & Fujiura, G., 1993; Melville, C. A., Cooper, S. A., McGrother, C. W., Thorp, C. F., & Collacott, R., 2005) higher risk of cardiovascular disease when older (Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W., 1999), and higher levels of depression (Lunsky, Y., 2003).

Race is included in this study as a demographic variable due to racial and ethnic disparities in health care that exist in the general population, and that appear to extend to adults with mental retardation. One study of mortality data for persons with Down Syndrome found increasing median age at death for all races between 1968 and 1997, with the increase much greater for whites than for either blacks or other racial groups. For example, the median age at death in 1968 was 2 years for whites and 0 years for blacks and other racial groups. By 1997, the median age at death increased to 50 years for whites, but only to 25 for blacks and 11 years for other races. The rate of increase in median age at death, however, was higher after 1992 for blacks and other races than for whites (Friedman, JM, 2001). Another study found increased bone mineral density for African Americans with mental retardation, similar to the general population (Tyler, C. V., Jr., Snyder, C. W., & Zyzanski, S., 2000), and a study by Anderson and colleagues of the 1994 and 1995 NHIS-D indicated that those with race other than Caucasian were more likely to have unmet health needs (Anderson, L., Larson, S., Lakin, C., & Kwak, N., 2003).

4.1.7 Discussion

The focus groups, interviews and literature review produced a list of potential instrument domains, each of which fits into at least one of the ICF domains. The five ICF domains are body functions/structures, activities, participation, environment and personal factors. Fourteen of the potential instrument domains fit into the body functions/structures ICF domain, including cardiovascular, dementia, dental, presence of Down Syndrome, presence of epilepsy, gastrointestinal, hearing, level of mental retardation, mental health, respiratory, skin, vision, and weight/BMI. Four potential instrument domains fall into the activities ICF domain, including feeding skills, independence in decision making, mobility, and self-help skills. Ten potential instrument domains fall into the participation ICF domain, including cues, dental, diet, exercise, health care utilization, injuries, medications, social/recreational, sun exposure, and tobacco use. Three potential instrument domains are in the environmental ICF domain, including care coordination, provider/health system related, and social/recreational. Three potential instrument domains fall into the personal factors ICF domain, including age, gender and race. It should be noted that some potential instrument domains fall into more than one ICF domain. Further, questions were not developed for each potential instrument domain. See Appendix F for a list of all of the potential instrument domains, the corresponding ICF domains, potential questions, and sources. Chapter 5 describes the development of the instrument in detail.

There were some variations in the types of issues raised between the sources with interview participants more likely to speak out about individual health concerns, but there were a number of issues that were identified by all, or most, of the sources. Issues raised by all four sources include dental health, provider/health system issues, and weight/BMI. Issues raised by three of the four sources include care coordination, presence of Down Syndrome, diet, exercise, mental health, social/recreational activities and opportunities, and vision.

Overall, systemic health issues were of greater concern to most family caregivers than individual concerns about the health of their family member. This was true for interview and focus group participants, despite the greater willingness of interview participants to speak about individual health concerns. There are a variety of possible explanations for this, some of which were noted by the experts. It is possible that participants, who knew that the results would be presented to OMR, viewed this as opportunity to advocate for system change and therefore were more vocal that they otherwise would have been. The small sample size and recruitment methods may have resulted in a sample of participants who are more likely to be vocal about systemic issues. It is also possible that systemic health issues are, in fact, of greater significance to the participants at this point in time. Regardless of the reason, it seems this area may benefit from further exploration to determine if this finding is an anomaly, or if there are significant issues that require governmental intervention.

5.0 THE INSTRUMENT

The goal of this project was to develop a health assessment instrument for family caregivers of adults with mental retardation. The results of focus groups, individual and expert interviews and a literature review were used to develop potential instrument domains, which were shared with experts for comment and clarification. Concurrent with those steps, an additional literature review was conducted to identify existing health assessment instruments that have been, or could be, used with adults with mental retardation. This is consistent with recommendations that researchers should attempt to utilize existing instruments before developing a new one (McDowell, Ian & Newell, Claire, 1987). The instrument domains were then finalized using the ICF domains (body function/structures, activities, participation, environment and personal factors) as a guide, and a draft instrument was developed and pretested. Specific steps in this process are listed below.

Instrument Development Steps

1. Solicitation of potential domains and opinions on health assessment instruments from focus groups and individual interviews.
2. Review of literature regarding the identified risk factors for disease in this population.
3. Solicitation of comments and reactions from experts on the above results.

4. Analysis of the results of steps 1 – 3, and development of potential instrument domains.
5. Examination of existing instruments for content in each identified domain, and formally requesting permission to use any copyrighted material.
6. Development of questions for each domain where existing instruments were not available.
7. Development and formatting the draft instrument.
8. Pretesting the draft instrument with a sample of earlier participants and the experts.
9. Review of pretest results and determination of the need for, and feasibility of, changes.
10. Modifications to instrument.

The previous chapter provided a summary of the domains that resulted from the focus groups, interviews, and literature. This chapter will explain the development of the instrument, beginning with the comments of participants on the subject.

5.1 PARTICIPANT COMMENTS ABOUT THE INSTRUMENT

Overall, study participants voiced apprehension that a health assessment instrument would be of benefit to them or their family member. In the words of one focus group participant, “Having something where, you know, you rate 1, 2, 3, 4, 5 is useless. A family member is not going to get anything out of that…You already have an impression of their overall health.”

A few participants felt that an assessment instrument could be helpful for caregivers who are unskilled, very young or elderly. One participant stated “When you first become aware in the hospital that you’ve had a life changing event and you’re in shock and now you are trying to figure out what you are supposed to be doing in this new world, OK, the next five years are a tumultuous mystery. As you try to determine what is available, what are the issues, how you address them, these kinds of assessments that you are talking about are useful at the beginning and end.” Another felt that the instrument would not help unskilled caregivers, stating ‘If they have been doing it for years and aren’t doing it so well, I’m not sure a tool is going to fix that problem.”

Reaction was quite negative within one group, where participants felt that this initiative was intrusive and constituted government meddling into their affairs, likening it to pressure that they felt from health care providers to place their family members into state operated institutions.

[Person 1]: “If you know the person you are caring for, you know what is best for that person.”

[Person 2]: “And the government shouldn’t be interfering.”

[Person 1]: “Absolutely not”

[Person 2]: “In family decisions”

[Person 1]: “My mother was told to put my brother in the institution”

[Person 2]: “My pediatrician told me that”

[Person 1]: “mmm hmm”

[Person 3]: “They should ***all*** be shot”

In contrast, many participants expressed the desire to receive assistance with *tracking* the health needs of their family member, including medications, medical appointments, and health milestones. In the words of one of the interview participants, “Some of this gets lost forever.”

When asked to comment on what should be included in an instrument of any type, the reaction was more positive, with participants eager to share their opinions. Participants suggested that the instrument should be individualized, allow for the family member to help complete it to the extent possible, and include questions about primary care providers, family member health needs, unmet health needs, cues to declining health, weight, blood pressure, behavioral issues, communication abilities, quality of life, access to health care, and aging issues.

Experts, who were asked to comment on these findings, had a variety of possible explanations for the negative reaction to the concept of a health assessment instrument. The parent expert indicated, initially, that she did not agree with the findings, stating that anything that provided her with more information was helpful. However, she also indicated that she obtains extensive health information from her local Health Care Quality Unit (HCQU) already, and really doesn’t need more. “Our families know this stuff,” she said. She indicated that while other parents who were less involved and assertive might benefit from using such a tool, they already are saturated with forms to complete.

Other experts thought it was possible that parents couldn’t visualize what the instrument would look like or how it would be used because the area of health promotion for this population has been overlooked. Several experts thought that due to recruitment methods, the participants who self-selected for the study were more likely to feel confident in their health monitoring abilities, and less likely to indicate that they would benefit from such a tool. One expert pointed to what was felt to be a significant disconnect between what participants stated that they wanted in a health assessment tool, and the tool being developed in this study, stating that the results were very clear – people don't want this tool. The physician expert noted that disinterest in a health assessment tool could be related to the aversion to the medical model, which dominated the mental retardation service delivery system for many years. Another expert felt that the fact that parents felt a health assessment instrument was not necessary was probably the very reason that one *was* necessary, stating "they don't know what they don't know."

Several experts felt that there might be some value to developing a hybrid instrument, with elements of tracking combined with assessment, and a few felt that there may be some benefit to the ISC completing this type of tool, perhaps as part of the annual planning process for each person. Several experts commented that there are tracking tools available already, and one expert indicated that tracking tools are not effective. Another expert felt that if the instrument provides parents with some type of tracking mechanism or checklist of some sort, it might encourage them to pay greater attention to health issues, and seek/demand more comprehensive medical care, as with dental care, for example.

Several experts felt that there should not be a separate health assessment instrument for this population, and that 'health problems are health problems.' "Don't we have more in common than not?" one asked. "Why do we feel that we need a different tool?" One expert commented that the public health system should be more inclusive of people with mental retardation and all types of disabilities and there should not be segregated systems or special instruments. This expert further stated that effective public health interventions should be available and useful for individuals with mental retardation, and if we are not sure that is the case, then *that* should change. This expert stated further that we should reconsider developing this instrument at all, or step back and gather additional data first about what might actually be helpful.

This same expert relayed an example of how the strategy of advocating for public health inclusion, as described above, has been applied. In the community where this organization is based, a local fitness-promoting organization recently distributed grant money for an initiative to promote physical activity. Initially discouraged by the fact that no funds were allocated to disability organizations, this advocate instead decided to approach the organizations that received grants to work with them to make their programs and initiatives more inclusive of individuals with mental retardation and other disabilities. This expert suggested that public health resources and interventions should be directed in this way, and not toward separate systems and interventions.

Finally, this expert also relayed that most people in the general public would probably not find assessment instruments of any type to be of benefit, therefore why would we expect parents of adults with mental retardation to feel otherwise? This expert also felt that it would be very interesting to know how the general public feels about health assessment instruments, and if the opinions of parents of individuals with mental retardation are consistent with the general population.

The physician expert noted that court cases and government regulation generate a fear of liability in the medical community, resulting in a drive for unnecessary health care and health risk assessment. “We overdo medical care, due to fear. People go to the doctor too much.” This expert felt that people are more aggressive with the health care of others than they are with themselves, particularly when they are responsible for that person in some way. “Health promotion is out there for all, but when you are responsible for someone else, you do more for them than you do for yourself." His point seemed to be that this initiative might be reflective of that same overprotection that he believes exists in the field of mental retardation.

Overall, therefore, the opinions of study participants were largely negative about the need for a health assessment instrument for adults with mental retardation, and the experts, for the most part, concurred. The reasons for the negativity are not clear, and it remains to be seen if some of the apprehension on the part of caregivers was related to the lack of familiarity with health promotion and assessment in this population. This explanation seems plausible, at least in part, when one considers the results of the pretest, which are explained later in this chapter. Experts were reacting to the caregiver comments, as they were asked to do, so their comments may have varied had their task been presently to them differently.

5.2 EXAMINATION OF EXISTING INSTRUMENTS

Existing health assessment instruments were evaluated to determine their suitability for use, in part or in full, with adults with mental retardation residing with their families. Two separate reviews were conducted: one related to instruments developed for adults with mental retardation, and the other related to instruments developed for other populations or the general public.

5.2.1 Assessment Tools for Individuals with MR

Health assessment tools for this population are limited in number, and most have not been subjected to extensive reliability and validity testing. Six such instruments were identified, including two that became available after this study began. They include the McGowen

Associates ‘Health Risk Screening Tool,’ the Pennsylvania ‘Health Risk Profile’ (PA-HRP), the University of Montana ‘Health and Secondary Conditions Surveillance Instrument for Adults with Developmental Disabilities,’ the ‘Greater Rochester Area Health Status Survey,’ the AAMR ‘Supports Intensity Scale,’ and the ‘Stay Well and Healthy!’ instrument.

The ‘Health Risk Screening Tool’ was developed by Karen McGowen of McGowen Associates to screen for health risks associated with developmental and physical disabilities for those receiving supports from community residential programs (McGowen, Karen Green & Smith, Carolyn J, 2002). It was later expanded to screen for conditions associated with aging. The instrument screens for 22 health indicators in 5 categories – functional status, behaviors, physiological issues, safety and frequency of health service use. Each area is rated on a five-point scale ranging from 0, indicating no health concern in that area, to 4, indicating strong concern. The points are totaled, with physiological issues doubled in weight, and one of 6 levels of health risk is assigned, with level 1 indicating low risk and level 6 indicating the highest risk. The instrument is commercial in nature, designed to be completed by residential staff, and available for purchase in either paper or electronic form. Information about testing for reliability or validity is not available. This instrument, with its clinical orientation, was not suitable for use in this study.

The Pennsylvania ‘Health Risk Profile’ (Commonwealth of Pennsylvania, 2001) was developed in late 1997 and 1998 to screen for physical and behavioral risk factors and the provision of healthcare services for people with mental retardation who had left, or were in the process of leaving, state facilities. The instrument has three parts, two of which are completed by residential staff and capture demographic and health related information, with the third part completed by a registered nurse. The instrument results in a risk rating ranging from low (less than one diagnosis with minimal or no effect on ADLs) to high (at least one diagnosis needing at least a monthly visit from a medically licensed personnel), and there is also an ‘unspecified’ category. The instrument was used in 1998 to assess the health needs of 564 people who had moved into the community from three state operated facilities, or who were in the process of moving. A reliability analysis conducted by Dr. Howard Degenholtz of the University of Pittsburgh Center for Bioethics and Health Law (Commonwealth of Pennsylvania, 1999) found that reliability was good overall, with most of the 11 variables studied found to have high reliability. Two others were found to have acceptable reliability, while one demographic variable dealing with the type of residential program was found to have low reliability. The instrument under development is designed to be a companion to the Health Risk Profile, which requires professional administration and is geared toward the residential population.

The ‘Health and Secondary Conditions Surveillance Instrument for Adults with Developmental Disabilities’ was developed by the University of Montana Research and Training Center on Rural Rehabilitation Services (RTC Rural), and the first report using the tool was published in 1998 (Szalda-Petree, A. & Traci, M. A., 1998). The instrument is an 18-page questionnaire measuring demographic information, overall health, health care accessibility and utilization, the prevalence and extent of limitation of secondary conditions, and stress/life changes. A total of 44 conditions divided into three categories (observed, possible, and supplementary/mobility impairment related conditions) are measured on a 4 point likert scale, with 0 representing no limitation and 3 representing significant limitation. Reliability testing was completed (Traci, Meg Ann, 2000) with ratings of 87%, but there is no evidence that validity testing was conducted. The instrument is comprehensive but it is also complex, making its applicability outside of the professional mental retardation service system, and in this study, impossible.

The ‘Greater Rochester Area Health Status Survey’ (Janicki, M. P. et al., 2002) was developed in 1999 by Dr. Matthew Janicki of the University of Illinois at Chicago and Dr. Phil Davidson of the University of Rochester for use in a study of the health characteristics and utilization of older adults with intellectual disabilities living in community residential programs in New York state. The instrument is a 4-page questionnaire consisting of 5 parts and 50 questions measuring demographics, diseases/conditions, personal skills, accident and injury history, and health service utilization. The instrument is well designed and comprehensive, but other than a pilot test in a small number of facilities, evidence of testing for either reliability or validity is not available. It was designed specifically to assess the health status of adults over the age of forty. The developers of this instrument provided consent for use of their material in this study, and in the instrument under development.

The ‘Supports Intensity Scale (SIS)’ was developed by the American Association on Mental Retardation (AAMR) and released in late 2004. The SIS measures the support needs of adults with mental retardation and is used by states, including Pennsylvania, to allocate resources according to need. The instrument measures support needs in the areas of home living, community living, lifelong learning, employment, health and safety, social, protection and advocacy, exceptional medical and behavioral supports. The SIS is designed for completion by an educated interviewer who has undergone training. It has 86 questions and 8 pages, is administered via a semi-structured interview, and was tested for reliability and validity (Thompson, J. R. et al., 2002). The SIS is not a health assessment, and provides no health education material directly to the individual or their caregiver. While the health related questions might provide some guidance in the development of domains for the instrument under development, the SIS is not a suitable tool for the purpose of this study.

The instrument that is the most similar to the one being developed was not available at the start of this study. This instrument, called ‘Stay Well and Healthy!’ was developed by Dr. Harriot Udin Aronow of the University of La Verne, CA and Dr. Joan Earle Hahn of UCLA (Aronow, Harriet Udin & Hahn, Joan Earle, 2005). This instrument was piloted as the lesser of two interventions for adults with mental retardation living with their families and in community-based group homes, with the other intervention a home visit from an advance practice nurse. The instrument was administered by an interviewer, and questions were directed to the individual with proxy participation only when necessary. A feedback mechanism is part of the instrument, with follow-up information provided following completion of the instrument. After some modifications to make the tool less complex and easier to understand, it was found by most participants to be easy to use. Administration of the instrument during the pilot resulted in a finding that large numbers of participants had not received preventive health screenings appropriate to their age and gender, including hearing, vision, blood pressure, gynecological, cholesterol, or occult blood.

The ‘Stay Well and Healthy!’ instrument includes 35 separate items in 3 categories: demographics, access to health care, and health status and risk factors. Many, but not all, of the health risks and risk factors identified in this study are included in the Stay Well and Healthy! instrument, including seizures, GI disorders, tobacco, sensory impairments, oral health, injuries, exercise, weight/height, and emotional well-being. A formal request was made to Dr. Aronow and Dr. Hahn to obtain an evaluation copy of the instrument, but a response was not received in advance of completion of this study. It is recommended that OMR continue to pursue obtaining an evaluation copy of this instrument (see Chapter 6 for detailed discussion of recommendations).

5.2.2 Assessment Tools for Other Populations or the General Public

A number of other health assessment instruments were reviewed for their potential applicability in this study. Some were generic instruments designed for the general public. Others, and the ones that were the most applicable, were designed to assess health risk in the elderly. None of the instruments examined, without modification, was appropriate for use in this study due to excessive length or complexity, a focus on reports of self-reported feelings of well-being or discomfort, clinical administration and/or interpretation, and lack of evidence of applicability of the instrument with adults with retardation or their families. At the same time, however, many of these instruments include some of the same domains identified as desirable in the instrument under development. As such, the instruments are of value for their use in guiding the development of questions, to the extent permitted by the authors.

The SF-36 is widely used in clinical and academic settings and with various groups, and has been tested extensively for reliability and validity (Ware, J. E., Jr. & Sherbourne, C. D., 1992). The self-administered version of the tool includes 36 questions measuring physical and mental health and well-being. There is no feedback mechanism, but due to its wide scale use and extensive evidence of reliability and validity, it was hoped that at least some of its questions could be used in the instrument under development.

Two studies were located where applicability to individuals with retardation was examined. In one study, the SF-36 was examined for reliability when completed by staff proxies in group living arrangements for adults with learning disabilities in the United Kingdom. The study found acceptable internal reliability and inter-rater reliability and a factor structure similar to that of the original scale (Jones, J, Dagnan, D., & Ruddick, L., 1997). In another study, the SF-36 was modified to include scales measuring sensory and memory functioning, and was administered verbally to adults with learning disabilities. The researchers found good reliability for measures of physical functioning, general health and pain, but poor reliability for sensory functioning and mental health (Ruddick, L. & Oliver, C., 2005). The authors of both studies were contacted to obtain additional information and evaluation copies of their revisions, but there was no response. In addition, the SF-36 cannot be used without permission from Quality Metric Health Outcomes Solutions. Quality Metric granted permission for the use of the SF-36 in this study for educational purposes only, but not in the final instrument as used by OMR. As the intent of this study is to provide OMR with a useful tool, the SF-36 could not be used for question content.

Two health risk assessment instruments for the elderly showed promise in their potential applicability in this study, and with this population. They are the Health Risk Assessment for the Elderly (HRA-E), developed by Dr. Lester Breslow and colleagues at UCLA (Breslow, L. et al., 1997), and the Health Risk Assessment for Older Persons (HRA-O), an adaptation of the HRA-E, developed by Dr. Andreas Stuck and colleagues in Germany, Switzerland and the United Kingdom (Stuck, A. E. et al., 2002). The HRA-E was designed to measure health risk and functional impairment in an elderly, community-residing, population. It is a self-administered instrument, with feedback provided after completion of the instrument and return to the researchers. Dr. Breslow agreed to release an evaluation copy to this researcher for the purpose of this study, but it was not received until after this study was complete.

The HRA-O was based on the HRA-E, with several modifications to make it culturally applicable in the countries in which it was administered. Dr. Stuck released an evaluation copy of the instrument, which was reviewed for applicability. The instrument is extensive, and includes 277 questions over 33 pages. It measures the following domains: medical history, health measurements, medications, signs and symptoms, bladder control, pain, oral health, vision, hearing, psychosocial health and well-being, social network, functioning, tobacco and alcohol use, physical activity, nutrition, injury prevention, preventive care, occupation and retirement, and demographics. The instrument was tested for feasibility by Stuck and colleagues, and was found by most users to be easy to use and understand. Completion time was just under 35 minutes (Stuck, A. E. et al., 2002). In a later study, Dr. Steve Iliffe and colleagues tested the HRA-O in a large group practice in the United Kingdom. Again, most users reported the survey to be easy to use and understand (Iliffe, S., Kharicha, K., Harari, D., Swift, C., & Stuck, A. E., 2005). Ultimately, no questions were used from the HRA-O, so permission was not sought.

The HRA-O and HRA-E have many similarities to the instrument under development. They are self-administered to a community-based population, some of whom have (age-related) cognitive impairments. They measure many of the same domains, including tobacco and alcohol use, injuries, and preventive health care. Finally, they provide a feedback mechanism, which is desired by OMR as part of their implementation of this instrument.

Several specialized public domain instruments were evaluated and ultimately used in this study. They include the Lubben Social Network Scale (LSNS) and the National Cancer Institute nutrition surveys. Not all questions from these instruments were used and, in one case, questions were included in the pretest but later removed from the final instrument. In most cases, minor modifications were made to the questions to allow for caregiver (proxy) report.

The LSNS was created by Dr. James Lubben of Boston College to assess social isolation in older adults. The scale is available in three different versions, has been tested for reliability (Lubben, J. E., 2002; Nahm, E. S., Resnick, B., & Gaines, J., 2004; Tang, W. K., Lum, C. M., Ng, K. Y., Ungvari, G. S., & Chiu, H. F., 2006), and has been used extensively in other studies (Lubben). There is no evidence of it having been used to assess social isolation among adults with mental retardation.

Three public domain nutrition survey instruments were used, including the Diet History Questionnaire, the Multifactor Screener in the 2000 NHIS Cancer Control Module (CCM), and the Percent Energy from Fat Screener, (National Cancer Institute Quick Food Scan). The Diet History Questionnaire (DHQ-1), referred to as a food frequency questionnaire or FFQ, is a self-report instrument consisting of 142 questions over 36 pages, and takes about an hour to complete. The instrument has been used in several studies and there is some evidence of validity testing, with the caveat that one study found significant underreporting of fat and protein intake using the DHQ-1, similar to other studies of similar instruments (Subar, A. F. et al., 2003).

The Percent Energy from Fat Screener was developed in 1996 by the National Cancer Institute as a short form dietary screening tool. The instrument is one page and consists of three questions, one of which consists of 15 subparts. There is some evidence of validity, with testing by the National Cancer Institute (Thompson, F. E. et al., 1998) and in a separate study which compared the results of a mailed survey using the Percent Energy from Fat Screener, with a telephone survey using the longer DHQ-1 (Snyder, D. C. et al., 2004).

Finally, the Multifactor Screener in the 2000 NHIS Cancer Control Module (CCM) is used to assess intake of fruits and vegetables, percent intake from fat, and fiber, and consists of 4 pages and 16 questions. Some evidence of validity was reported when results were compared with results using other similar measures (Thompson, F. E. et al., 2005; Thompson, F. E. et al., 2004).

These instruments were the only public domain instruments felt to be relevant to this study. There are numerous disability-type assessments available, but in addition to being outside the public domain, most focus on issues of concern to people with physical, and not cognitive, disabilities. Similarly, many general health assessment instruments focus on health related quality of life, and are narrow in focus. For example, the EQ5D (Rabin, R. & de Charro, F., 2001) is brief and available for public use, but its focus is too narrow to be of use in this study. The EQ5D consists of 5 questions, including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression with three responses each. The self-care question, for example, has three responses, including 'I have no problems with self-care', 'I have some problems washing or dressing myself', and 'I am unable to wash or dress myself.' It is likely that many adults with mental retardation will need some assistance or prompting to perform these self-care tasks appropriately, but that would not necessarily indicate ill health or even a reduced quality of life. The EQ5D lacks the depth necessary to assess the health of this population. The EQ5D does include a visual analogue scale where users are asked to plot their overall health, but it takes up a full page, so ultimately, it was rejected in favor of another question type. At least one study found low validity in use of proxy reporting for the EQ5D (Tamim, H., McCusker, J., & Dendukuri, N., 2002).

5.3 DEVELOPMENT OF THE INSTRUMENT

5.3.1 Procedures

The qualitative methods used in this study provided information about the health issues of, and health risk factors for, adults with mental retardation, in addition to the opinions of family caregivers and experts on health assessment instruments, which were largely negative and in conflict with the goals of the study. Participants were clear in their desire for a tool to help them manage the details of, but not to assess, their family member's health. Initially, upon consideration of those findings, an attempt was made to develop the instrument as a hybrid, with elements of tracking included in the assessment instrument. Ultimately, that goal was rejected, as it became evident that a hybrid instrument would have been too complex. The instrument was, therefore, developed consistent with the original intent of the project, to assess the health of individuals, with the hope that the tracking needs could be met in some other way.

To develop the instrument, each potential instrument domain resulting from the analysis of the qualitative findings was first plotted on a grid listing the sources (focus groups, individual interviews, literature review or expert interviews) for each. The potential domains were sorted, with those identified by the most sources at the top. Those identified by the most sources were prioritized for inclusion in the study, unless there was some other reason to justify exclusion, with those noted by the fewest number of sources having the lowest priority for inclusion.

Questions were then developed to address each domain. Questions were added related to demographics (like name and address), and several questions were added to assess health risk for conditions that are common and potentially problematic in adults with mental retardation (like cerebral palsy and thyroid disease), or that result in high mortality in the general population, (cancer), despite not having been noted by any of the sources. In addition, some questions were eliminated and some domains ignored where it was felt that including them would make the instrument unnecessarily lengthy and/or complex. The questions were then grouped into categories to assist in instrument design, and the first draft of the instrument was developed and named "Let's Get Healthy Together!"

Consent to use content from other instruments was only received from the developers of the Greater Rochester Area Health Status Survey, Dr. Matthew Janicki and Dr. Phil Davidson. The HRA-E was received following completion of the study. Public domain instruments were used wherever possible, but few existed that met the needs of this study. Most questions, therefore, were created specifically for this instrument.

Following development of the first draft of the instrument, the OMR medical director was consulted for expert review, and some preliminary changes were made based on their advice. These changes were primarily related to clinical concepts and terminology, with some additional questions developed to provide depth in a particular area of health risk. The instrument was modified based on their recommendations and copies were made at a local office supply store. Two versions were produced, one large version that, when printed in booklet form has a page size of 8 ½ by 11 inches, and a smaller booklet that with page sizes of 7 by 8 ½ inches.

Each expert was provided with one copy of each version and asked to comment. The parent expert was asked to complete the instrument and return it, similar to the other family member pretest participants. Experts, except for the parent, provided written comments, which were then used to guide the interviews with the pretest participants.

Five pretest participants were selected randomly from among those who participated in focus groups or interviews and said they would be willing to assist. Each person was contacted to verify their continued interest and was advised of the expectations for their participation and next steps. Of the initial five people who were selected, one said that personal issues precluded her participation, and another could not be reached due to her phone number and email address having been changed. Two additional people were selected at random from those remaining, and they agree to participate. The five participants were mailed one copy of each version and advised to complete the large one and return it in a self-addressed, stamped envelope. A cover letter was sent along with the instruments to provide a reminder about the purpose of the study and instructions for completing and returning the instrument.

Following receipt of the completed instrument, each participant was contacted to schedule a time for a personal telephone interview. A semi-structured interview questionnaire was developed based on the expert comments, review of the completed and returned surveys, and my own impression of questions that might have been confusing. Telephone interviews were conducted with four of the five family participants, and with the parent expert, with parents referring to the smaller version that they had been advised to keep. One family participant returned the survey after the pretest had been concluded, and those results are not included here.

The pretest results were analyzed, recommendations prepared, and the OMR medical director consulted again for guidance. Changes were made based on the pretest results and ensuing discussion with the OMR medical director, and a revised version of the instrument prepared. The final version, which is included in Appendix G, consists of 64 questions and 20 pages.

5.3.2 Content

Questions were developed for each domain and are discussed here in the context of the ICF domains. See Appendix F for a list of the instrument domains, the corresponding ICF domains, and resulting questions. Unless otherwise noted, all questions were developed specifically for this instrument. Any significant modifications of the instrument due to the pretest results are noted in each section below, as applicable.

5.3.2.1 Questions related to the Body Function/Structures ICF Domain

This ICF domain refers to the actual structure of the body, with its strengths and limitations. Sixteen separate issues were raised that fall into this ICF domain. Two of them, dental health and weight/BMI were noted by all four sources as being of importance. Dental health falls into several other ICF domains as well, including participation and environment. As the instrument questions focused on dental issues that fall into those other domains, dental issues will be explained later in this chapter. Three issues, presence of Down Syndrome, mental health, and vision, were noted by three sources. Another five issues were noted by two sources, and remaining issues were noted by only one source.

Weight/BMI: Four questions were developed to assess weight/BMI. Height and weight questions (24 and 25) will allow for a BMI calculation to be completed after the survey is submitted to OMR. Two additional questions measure whether the caregiver believes that the individual needs to lose weight, and whether the individual agrees. These two questions will provide OMR with information about any education that may need to be done with caregivers about healthy weight (based on the BMI calculation), and with individuals, on a one-to-one basis or broad scale.

Presence of Down Syndrome: This question, 14A, is part of a series of questions about any other conditions/diagnoses that the individual has. This is included out of recognition that individuals with Down Syndrome have elevated risk for a variety of conditions, and for increased mortality, concern for which was raised by several participants.

Mental Health: Locating questions to assess the mental health risks of adults with mental retardation was difficult. As noted earlier, diagnosing mental illness in those with retardation is complex, and over-diagnosis is common. Due to the complexity of the subject and the lack of available public-domain proxy-report instruments, questions were not developed to attempt to assess the mental health of participants. Instead, questions were asked to determine if the individual was diagnosed with, or takes medications for, a mental illness (14S, 23H, 23I). The existence of a mental illness may make health promotion with the individual and his/her caregiver more difficult, and psychiatric medications can have significant negative side-effects.

Vision: Visual disorders occur at higher rates for those with mental retardation, and in particular, Down Syndrome, and they are frequently undiagnosed and untreated. There are three questions in this area (14R, 15E and 16D), designed to determine if the individual wears glasses, has a family history of glaucoma, and to assess if the caregiver feels that there has been any change in his/her ability to see.

Cardiovascular: It is known that individuals with Down Syndrome are at higher risk for certain cardiovascular conditions, and that individuals with mental retardation have higher rates of obesity, which is a risk factor for cardiovascular disease. While some studies have shown reduced rates of cardiovascular disease compared to the general population, the data are limited. Cardiovascular diseases are among the top three causes of mortality in the general population of the United States (National Center for Health Statistics, 2005), and therefore, a heavy emphasis was placed on this domain, and on other factors that contribute to cardiovascular risk, like obesity, physical activity, and diet. Nineteen questions were developed to assess cardiovascular risk, including one about the presence of diabetes (14E), which is a risk factor for cardiovascular disease, one about high blood pressure (14F), high cholesterol (14G), three questions about heart defects from birth (14H, I and J), questions about having had a heart attack (14K), congestive heart failure (14L), and a stroke (14M), questions about family history of diabetes (15A), high blood pressure (15B), high cholesterol (15C), heart disease (15D), questions about medications taken for high cholesterol (23A), high blood pressure (23B), diabetes (23C), heart disease (23G), and whether or not the individual has been screened for diabetes (48C) or high cholesterol (48D).

Dementia. Down Syndrome is a risk factor for early onset Alzheimer's disease, but due to the complexity of measurement of dementia, the first draft of the instrument excluded this domain. Two pretest participants noticed its absence, however, so the revised version included three questions designed to assess any change in the last 12 months in memory (16A), communication skills (16B), or ability to perform routine activities (16C). Loss of function in these three areas is one of the signs of early Alzheimer's disease (Janicki, M. P., Heller, T., Seltzer, Gary B., & Hogg, James, 1995).

Gastrointestinal Disorders: Two sources noted gastrointestinal disorders as concerns. Three questions were included to assess the presence of a disorder (23E), and feeding/swallowing skills (26 and 27), which are related to this area but also risk factors for other conditions and for increased mortality and morbidity.

Respiratory Disorders. Two sources noted respiratory disorders as risk factors for other health concerns, and two questions were included. One asks if the individual has any type of lung disease and asks them to describe it (14I), and another asks if they are taking medication for asthma (23D).

Skin Disorders. Skin disorders are frequently untreated in this population. Two questions were included to assess the presence of chronic skin ulcers (14N) and skin rashes (14O).

Other. Allergies, presence of epilepsy, hearing, and level of MR were noted by one source each as being significant. The **allergy** issue was brought up during an interview. No questions were developed to assess this issue, due to the goal of keeping the instrument as short as possible. Presence of **epilepsy** was assessed in two questions, one of which asked if there was a diagnosis (14C), and the other which asked if the person was taking any medications (23F) for the condition. Presence of **cerebral palsy** was assessed in one question, 14B, despite it not be mentioned by any of the sources. While many people with cerebral palsy do not have mental retardation, its presence can result in additional health concerns and risks in those who do have mental retardation. Likewise, presence of a **thyroid** condition was included (14D) since it is very common in people with mental retardation (Kapell, D. et al., 1998). Given the fact that the second most common cause of death in the United States is **cancer** (National Center for Health Statistics, 2005), a variety of questions were included to assess presence and family history of, and risk factors for, cancer. These include 14P and Q, 14U and 15F – K, **Hearing** was assessed with one question (16E) designed to measure any change within the last 12 months. Finally, **level of MR** was assessed with one question (12).

5.3.2.2 Questions related to the Activities ICF Domain

This ICF domain measures the abilities of the individual, given his/her body/structures and other environmental/personal influences. Three domains were noted that fall into this category, with all of them resulting from the literature review. They include feeding skills, independence in decision making, mobility, and self-help skills. Questions were not developed to directly measure independence in decision making or self-help skills. Both are related, to a certain extent, to level of MR, and can be measured indirectly by other questions (mobility, level of MR, feeding skills). These areas were excluded primarily due to space considerations. Feeding skills were assessed with two questions (26, and 27), and mobility is measured with six questions, four of which assess the use of assistive devices to move around (17A – D), and two of which assess decline in ability within the last 12 months (18 and 19).

5.3.2.3 Questions related to the Participation ICF Domain

This domain measures the actual involvement of the individual, given their body function/structures, abilities, and the environmental influences. Dental health was mentioned by all four sources, but primarily related to use of dental care and access barriers. Three domains that fall into this category, diet, exercise and social activities, were mentioned by three sources each. The remaining six domains were noted by two sources each.

Oral Health: Four questions were developed to address the dental concerns for this population. They include questions about brushing and flossing habits, and frequency of, and payment for, dental visits. The frequency and payment questions were designed to assess dental health care utilization and any payment barriers that may exist.

Diet. Three separate sources noted diet to be a concern. 13 questions were developed to assess intake of fruits and vegetables (30A and B), and dietary fat (31A – N). Another question, 32, was developed to assess the frequency of low fat food choices. The first draft of the instrument included the fruit and vegetable questions, one question about consumption of bacon or sausage and another about hot dogs. Pretest participants expressed some confusion with the wording of the questions, and one expert wondered why users were not asked about consumption of ice cream or pizza. All diet questions were adapted from National Cancer Institute instruments. The fruit and vegetable questions were adapted from the Diet History Questionnaire (questions 131 and 132), and the bacon/sausage and hot dog questions were adapted from the Multifactor Screener in the 2000 NHIS Cancer Control Module (CCM). Based on the pretest comments, these last two questions were rolled into a series of questions designed to measure intake of dietary fat, adapted from the National Cancer Institute Quick Food Scan (National Cancer Institute, 2000).

In the pretest version of the instrument, there was a question asking the caregiver to assess the level of fat in the diet. Using the technique of probing (National Bureau of the Census, 2003; DeMaio, T., Mathiowetz, N., Rothgeb, J, Beach, M, & Durant, S, 1993), it was determined during the pretest that users defined the terms ‘low fat’, ‘medium fat’ and ‘high fat’ in different ways. This question, therefore, was removed from the final version and replaced with a question about the frequency of low fat food choices (32).

Exercise. Two questions were included to assess exercise, one designed to determine if the individual gets regular exercise (33) and the other designed to gauge the level of exertion (34).

Social Activities. Three sources noted participation in social activities to be critical to good health. One question, 9, asks how many people there are in the home. The idea here is that a larger household increases the support for family members, potentially increasing the likelihood of the individual being able to access social opportunities. The remaining questions (55 – 63) were adapted from the Lubben Social Network Scale (LSNS). The pretest version of the instrument included six questions from the LSNS, two each about relatives, neighbors and friends. One pretest participant commented that the questions were important, but didn’t speak to the quality of those relationships. The final version of the instrument, therefore, included an additional three questions designed to gauge quality.

Cues. Many study participants mentioned that looking for cues to their family member not feeling well was critical to their well-being. Seven questions were included that were designed to measure a change in the health of the individual. Questions 13A and B ask about overall health today and 12 months ago. These questions were adapted from the Greater Rochester Area Health Status Survey, whose developers provided consent for their use. The dementia questions, 16A – C, also assess change in health status, as do 16D and E, regarding any change in vision or hearing.

Health Care Utilization. This domain includes questions of two types – those that measure overall utilization of health care services, which can be a red flag for either under or over utilization based on the health status of the individual, and those that measure use of preventive health screenings, which several studies have found to be lacking in this population. The overall utilization questions, 49A – E, measure use of primary and specialty care, emergency rooms for illness or injury, and inpatient stays. The preventive screenings questions measure use of a variety of services and the performance of self-exams, and include mammograms (41A), pap smears (41B), breast cancer exams (44), bone density screenings (41C), prostate (45), testicular (46, 47) and colon cancer screenings (48A and B), diabetes (48C) and cholesterol (48D) screenings, and skin cancer screenings (52H). Overall, the reaction of pretest participants to these questions was very positive. Several stated that they appreciated being asked these questions because no one ever does, and that just answering these questions reminded them of tests they should think about getting for their family member. One parent of a 40 year old stated that she never thought about getting him a prostate exam, but that it was something she needed to do.

Injuries. One expert mentioned injuries as a concern, primarily related to the workplace, and the literature refers to injuries particularly with regard to those with seizure disorders or related to falls among those who are institutionalized. Several questions are included to measure risk from injuries, including 49D which asks about ER visits due to injuries, 53A about seat belt use, 53B about use of a helmet when bike riding, 53C about riding as a passenger with someone who drinks and drives, and 54 about a working smoke detector in the home. One participant stated that completing the pretest reminded her that she needs to get her smoke detector repaired and operational.

Medications. Polypharmacy is an issue in this population, as are the potential negative side-effects of both psychotropic and anti-epileptic medications. Questions 20 – 22 address the number of medications taken, the number of physicians prescribing them, and the communication between providers about the different medications. In addition, questions 23, A – J, ask users to identify the conditions for which medications are taken.

Sun Exposure. Sun exposure was mentioned by one expert as being an issue, and questions are included here both for that reason, and due to the link between sun exposure and skin cancer. Eight questions are included, 52 A-H, which ask if the individual has a large number of moles, freckles after being in the sun, has a history of blistering sunburn, wears sunglasses, burns easily, wears sunscreen, spends a lot of time outside, and receives regular skin checks for changes in moles. The reactions of pretest participants to these questions were also very positive.

Tobacco Use. Tobacco use is addressed by three questions which assess smoking habits (35 and 36) as well as exposure to second-hand smoke (37).

5.3.2.4 Questions related to the Personal Factors ICF Domain

Personal factors influence the individual and his/her body, skills and participation. The personal factors that are included in this instrument include age (8), gender (10) and race (11), as each have been found to be risk factors for a variety of conditions.

5.3.2.5 Questions related to the Environmental Factors ICF Domain

The environment influences, but is external to, the individual. Three domains fall into this category, one of which, provider/health system related issues, was noted by all four sources, and the other two, care coordination and social opportunities, which were noted by three out of the four sources. The goal of this instrument was to assess the health of the individual by asking questions related to the primary health issues of adults with retardation, in addition to the risk factors for disease and increased mortality. While the environmental issues are certainly part of the story for the health of this population, the purpose of the instrument was not to identify or attempt to modify those issues. Therefore, environmental influences were included in the survey in only a cursory way. It is hoped that the focus group and interview results will be carefully considered by OMR, and appropriate action taken to explore and/or correct the issues noted in this study.

Care coordination was not addressed with questions in this instrument, but it is hoped that ISC's may be able to play a role its future implementation, thereby potentially increasing their usefulness to parents. **Social/Recreational** issues cover two categories, one related to the actual participation of the individual, where there are ten questions included, and the other related to the environmental domain. There are no questions included that are designed to measure the barriers to participation in recreational opportunities, such as a lack of transportation or a lack of financial resources. These questions were excluded as they fell outside the scope of this instrument, and for the purpose of keeping it as short as possible. In addition, the significant negative reaction in the focus groups and interviews to the concept of a health assessment instrument seemed to indicate that asking personal questions related to finances would not be a good idea.

Several questions are included to measure **provider/health system** related influences, including type of medical insurance (50A – D), participation in managed care (51), and payment for dental care (40).

5.3.2.6 Additional Questions

In addition to the questions noted above that fit into the ICF domains, administrative/demographic questions were included. While such questions are usually included at the end of a survey, they were included here at the beginning, as the negativity expressed during the preliminary phase of the study seemed to indicate that putting the health questions second might make more sense. Questions 1 – 7 include the date, the name of the person completing the survey, the first name of the individual, the mailing address, phone number and email address, and the date of birth of the person completing the survey. At the very end of the survey, the last question, 64, asks for general comments.

5.3.3 Pretest Results and Modifications

The pretest consisted of several steps, beginning with OMR medical director review of the first draft of the instrument. After changes were made, a revised version was sent to experts and caregivers. The experts provided written feedback, which was used to develop an interview framework (Appendix H) for the caregiver interviews. Finally, the results were shared with

OMR's medical director again, and revisions were made based on the pretest results and OMR's input.

Overall, the reaction to the instrument was surprisingly positive in light of the negative opinions expressed earlier. While the sample of five caregivers is obviously very small, and certainly not representative of the population of potential survey users, the results were promising. All but one was very pleased with the instrument, stating that it was easy to use, took very little time to complete, and caused them to consider the need for preventive health services that they had not thought about earlier. The only caregiver who expressed concern stated that it was not long enough, was too easy to complete, and did not cover enough of the clinical issues of importance to her and her daughter with Down Syndrome.

Most participants preferred the larger version of the instrument, stating that it was easier to read. The oldest caregiver participant preferred the smaller one, stating that it was easier to handle. The average completion time was 17.4 minutes, with a range of 10 – 30 minutes. The person who took 30 minutes stated that she had frequent interruptions. All but one person read the instructions and found them easy to understand.

A number of suggestions were made about specific questions. For example, one person indicated that when asked for her name, she wasn't sure if she should complete her name or her family member's name, until several questions later when she saw the field for his name. As a result, the order was changed to move both name questions next to each other. The word 'elevated' was changed to 'high' throughout the document, and 'gastrointestinal' was changed to 'stomach', although the oldest participant stated that 'I didn't even finish the 8th grade and I understood what it [gastrointestinal] meant'.

One of the experts commented that the use of the term ‘heart disease’ in several questions in the first draft was confusing, so pretest participants were asked if they understood its meaning. They did not, leading to splitting several questions into specific conditions that are usually considered under the umbrella of ‘heart disease’.

The first version included several food related questions, which experts felt needed to be better defined and, perhaps, expanded. One question asked if their family member ate a diet that was low, medium or high in fat. Using the technique of probing, each pretest participant was asked to define a medium fat diet. Two of the five defined it in the same way, but the other three had widely varying definitions. As a result, this question was removed from the final version, and specific questions about consumption of high-fat food were added.

Several experts noted that some questions, such as those related to insurance, race, and gender-related screenings, might be considered sensitive, and some users might not want to respond. In contrast, however, all participants indicated that they had no problem with the questions. They stated that they are asked financial questions frequently, so they are used to them.

The feedback provided during the pretest interviews produced helpful suggestions for improving the instrument. In addition to the interviews, the returned surveys were analyzed for errors and omissions. Each occurrence was reviewed to determine if there was a problem with a question, or if it was potentially an aberration. One person appeared to have answered the race question, which excluded the terms ‘white’ and ‘black’ incorrectly. In the revised version, the options were modified to include those terms. The first version included three separate questions related to the risk factors for testicular cancer. After two participants failed to complete them, and upon consultation with the OMR medical director, the two least common risk factors were removed. The question designed to assess mobility include an option of ‘other,’ which two participants left blank. This option was removed from the final version.

One survey provided information about the potential problems with the food questions. One participant indicated that her son has a height and weight that result in a BMI of 51.3, which reflects morbid obesity, yet she also indicated that he gets regular, vigorous exercise several days a week, eats large quantities of fruits and vegetables, and rarely eats full fat bacon, sausage or hot dogs. This finding indicated that the food questions needed to be completely overhauled in the revised version.

6.0 DISCUSSION

This study resulted in the creation of a new caregiver-completed health assessment instrument for adults with mental retardation who live with their families, using existing instruments to the extent possible. The instrument can be used on an individual level to help educate caregivers to the health needs of their family member. There was some evidence from the pretest that caregivers viewed the instrument in this light. On a broader scale, the instrument can be used by OMR to generate data to identify population-based health issues and develop large-scale health promotion interventions.

The instrument was based on exploratory research identifying the health concerns and risk factors for adults with mental retardation, and the existing health assessment instruments used in both the mental retardation field and for the general population. There are no similar, publicly available, health assessment instruments for caregivers of adults with mental retardation, and those that are used for the general population have been largely untested in this population. As such, this study fills a gap in the literature, providing the foundation for further development and widespread testing and use of the instrument.

In addition to this product, the qualitative components of the study generated interesting results that merit further discussion and exploration. This chapter will provide a summary of the study limitations, the most significant issues raised, and recommendations for further testing and implementation of the instrument.

6.1 LIMITATIONS OF THE STUDY

6.1.1 Sample Size and Recruitment

Recruitment of focus group and individual interview participants was challenging, and the sample size was smaller than expected. While not uncommon for exploratory research, the sample is too small to reach conclusions about the issues raised or to assume that the results apply to any larger population. The sample is not representative of the population of caregivers of adults with mental retardation or their family members. There were no Hispanic participants, and only one African American participant, which is of great concern in light of the racial disparities in the health of people with mental retardation. The average age of individuals cared for by participants was younger than expected, and their level of mental retardation was more severe than the national averages of all people with mental retardation. Despite these limitations, the expressed concerns about the quality of the health care system in Pennsylvania for adults with mental retardation deserve further attention and exploration.

6.1.2 Proxy Reporting

Reliance on proxy reporting in this and other similar studies is potentially problematic. In proxy reporting, someone other than the subject of the assessment provides the information needed to complete the assessment. Numerous researchers have found significant bias, with proxies more likely to report lower functioning than respondents. Todorov and Kirchner found that use of proxies in the National Health Interview Survey (NHIS) resulted in bias, potentially affecting national disability estimates, with younger proxies likely to under report and older proxies likely to over report disabilities (Todorov, A. & Kirchner, C., 2000). Basset et al. found bias for proxy reporting, with proxies more likely to underrate affective status and overstate cognitive status in a study involving elderly urban women (Bassett, S. S., Magaziner, J., & Hebel, J. R., 1990).

Ready et al. found that proxy and self-perceptions differed in assessing quality of life for individuals with mild cognitive impairment and Alzheimer's disease, and concluded that both perspectives were valuable and should be taken into account (Ready, R. E., Ott, Brian R., & Grace, Janet, 2004). Andresen and Vahle found that proxies were more likely to overestimate impairment and underestimate health related quality of life, but underestimate pain in people with disabilities. They also found that agreement between the proxy and the individual were higher when the proxy was a relative than when the proxy was a friend or health care provider (Andresen, E. M., Vahle, V. J., & Lollar, D., 2001). In contrast to this finding, Ball et al. found less bias with professional proxies than with layperson proxies, finding that laypersons were more likely to report poorer functioning in older patients with physical disabilities (Ball, A. E., Russell, E. M., Seymour, D. G., Primrose, W. R., & Garratt, A. M., 2001).

In the area of mental retardation, available research is more limited, but is generally consistent with the finding of bias, with some important distinctions. Schwartz and Rabinovitz examined proxy bias in social workers and parents in reporting life satisfaction among adults with intellectual disability. When individuals were high functioning, they found significant bias in proxy reporting by social workers. Bias was not found with parent proxies for any level of functioning. The researchers concluded that parents are the preferred respondents when proxy reporting is necessary in this population (Schwartz, C. & Rabinovitz, S., 2003). Perry and Felce found significant bias in staff reporting of quality of life for individuals with mental retardation, with objective measures exhibiting less bias than subjective measures (Perry, J. & Felce, D., 2002).

The implication for the use of proxy reporting is that some degree of bias is inevitable. The likely nature and extent of bias is not clear, although there is some reason to believe that the use of a parent or family member may be the best choice. The existence of bias in this study that was introduced in the focus group and interview process and in the development of the instrument should be considered. OMR could consider developing a companion instrument for individuals to complete by themselves or with support from their family members, but doing so would introduce an entirely different set of challenges. Understanding that the purpose of this project was to develop an instrument for caregivers to better support the health of their family member, a small degree of bias is probably acceptable.

6.1.3 Lack of Research on Health Assessment in this Population

The literature review of health assessment techniques and instruments for this population resulted in a dearth of research on the subject. There are few self or proxy administered health assessment instruments for, or generic instruments that have been tested with, this population. Most of those that exist are designed for completion by a trained interviewer or a clinician, or their purpose is clinical management or resource allocation. Little is known about the benefits of such an instrument in this population. This study was undertaken, and the instrument developed, with a limited research foundation, and the results should be viewed in that light.

6.1.4 Lack of Psychometric Testing of Draft Instrument

While formal testing of the instrument for reliability or validity was not possible given time and resource constraints, validity can reasonably be assured by virtue of the care that was taken to develop an instrument that was reflective of the current level of knowledge of health issues for adults with mental retardation. This study involved a comprehensive exploration of health issues using a variety of methods, soliciting input from a diverse set of participants, and using domains culled from a large universe of existing health assessment instruments, many of which have been tested for validity. All are common techniques used to increase the likelihood of an instrument with content validity, which means that it measures what it is supposed to measure, that is comprehensive and representative of the possible questions that could be used to measure health.

Construct validity is related to the extent to which the instrument is consistent with its theoretical foundation. A clear conceptual framework is essential for construct validity, which can be tested by examining if the expected relationships in the data are consistent with that framework. While formal testing for construct validity was not possible, the links between the theoretical framework, the ICF domains or constructs, the instrument domains and the questions are clearly stated, providing a solid foundation for formal construct validity testing with the first implementation of the instrument.

6.2 KEY FINDINGS

6.2.1 Health Assessment

While nearly all participants saw no benefit in a health assessment instrument, a sample of those same participants reacted with great enthusiasm when asked to complete the draft instrument in the pretest. In fact, the only negative overall comment received during the pretest was from one parent who stated that it wasn't extensive enough to cover all of the clinical needs of her daughter with Down Syndrome.

There are several possible reasons for the dramatic shift in opinion about the value of a health assessment instrument. First, the small sample size for the pretest could have resulted in bias. Second, it is very likely that pretest participants were influenced by their earlier participation in the focus groups and interviews. Those discussions included an overview of the intent of the instrument, using the example of 'the types of surveys you fill out when you go to the doctor's office and they want to know how healthy you think you are compared to last year.' On the one hand, participants may have reacted negatively to the example that I provided, and not the instrument under development. My example was intentionally vague, as I didn't want participants to believe that I had a preconceived notion of what information the instrument would contain. That may have been the wrong approach, as participants may have substituted their own incorrect assumption of the instrument in place of one that I could have provided for them. On the other hand, their understanding of the instrument may have been correct, but the act of discussing it and, in the case of the focus groups, hearing others talk about it, may have educated them about the need for the tool and altered their opinion. Looking back, it probably would have been desirable to complete the pretest on a group of caregivers who did not participant in the focus groups or interviews. This would have removed any possibility of bias resulting from their earlier participation in the study. In addition, the focus groups and interviews could have been completed after development of the instrument, or at both stages, but with different groups of people. It is also important to note that the experts were asked to comment on the opinions of the focus group and interview participants, and it is not clear how they would have reacted had their task been presented to them differently. **OMR should conduct further testing of the instrument to eliminate this potential bias and obtain a valid opinion from participants on the value of the instrument.**

In addition, several of the experts raised a valid question, which is why there should be a separate instrument for adults with mental retardation. The research conducted in this study failed to identify health assessment instruments for the general population that could be used to address the varied health issues raised by participants and noted in the literature. Many such instruments are highly specific, being geared toward one particular disease. Others are generic, but measure such things as health related quality of life. Those types of measures are clearly of relevance to the population of adults with mental retardation, but are not inclusive enough of the conglomeration of the issues that have been found to impact their health, at least at this point in time. The instruments for the elderly are the most promising in their potential applicability to this population, and deserve further scrutiny. There is significant value in using an established instrument that has demonstrated reliability and validity, but few of these instruments have been examined for their relevance with adults with mental retardation. The new instrument in the mental retardation field, Stay Well and Healthy!, should be examined to determine if it could potentially meet the needs of OMR. The authors of that instrument did not respond to my requests for more information, but they may do so if requested by OMR. The recommendation is that **OMR should contact the authors of the Stay Well and Healthy! instrument to obtain an evaluation copy and determine if it will meet their needs. In addition, further research should be conducted to determine if existing instruments for the general population have relevance for the population of adults with mental retardation**.

6.2.2 Tracking

Most participants expressed the need for assistance in tracking the health care needs of, and services received by, their family member. In response, Let's Get Healthy Together! was initially developed to be a hybrid instrument, with elements of health assessment and tracking intertwined. Accomplishing both objectives in one instrument proved impossible, with the complexity outweighing any benefit. Viewing this unmet need of parents in conjunction with their comments about ISCs, it is evident that this is another area where ISCs may be able to provide further assistance, again improving their perceived value to caregivers. Therefore, **OMR should consider developing a tool to help parents and other caregivers track the health of, and health services received by, their family members. Secondly, they should consider whether ISCs can play an expanded role in meeting this unmet need of families**.

6.2.3 Care Coordination

Care coordination services received from the ISCs were heavily, although not universally, criticized. While some participants acknowledged that they were fortunate to have a good ISC, most that did stated that they believed it may have been because they were particularly vocal. Participants don't view ISCs as a resource in supporting their family member and instead consider them intrusive. Several participants seemed willing to consider a larger role for ISCs in managing the health of their family member and in securing needed health care services. It should be noted that the same potential bias that was acknowledged with regard to the provider findings could also have resulted in bias here. As OMR proceeds with its evaluation of the Let's Get Healthy Together! instrument, it should consider what role ISCs might be able to play in its implementation. Involving the ISCs could result in higher success with, and wider adoption of, this instrument, with the added benefit of allowing families to view ISCs in a more helpful role. **It is recommended that OMR consider using ISCs to implement this instrument**.

6.2.4 Provider/Health System Issues

Concerns with the quality of providers and the health care system were nearly universal, regardless of whether the participant attended a group or individual interview, where they lived, and what level of mental retardation their family member was diagnosed with. Such concerns, while important, were not directly related to this study, which was designed to identify the health concerns and risk factors for this population, and then develop an assessment instrument that could be used primarily to alert the family caregiver to these issues and, potentially, improve the health of the individual.

There are several explanations for the attention paid to these issues by participants, most of which have been noted earlier in this document. They include possible bias due to the recruitment methods, which may have resulted in over-recruitment of those who, on the one hand, are very vocal with their systemic concerns and, on the other, are particularly skilled and/or confident in handling medical issues for their family member. The sample sizes used throughout this study were small, and it is likely that the opinions expressed by participants are not representative of what a larger sample would have expressed. It is also possible that participants, who knew that the results were being presented to OMR, viewed it as an opportunity to voice their opinion and advocate for systems change.

Addressing these concerns within the Let's Get Healthy Together! instrument was challenging, as the primary intent of the project really was never to develop an instrument to assess environmental barriers to achieving positive health outcomes. Several questions were developed to address, in a minor way, these systemic concerns, but overall, this is a topic that is outside the scope of this project. At least one of the experts, a physician, acknowledged that the issues raised by participants are issues that he has tried to address, without success. Additional research is recommended to examine the health care provider and access issues described by participants as being barriers to good health outcomes for adults with mental retardation.

6.3 NEXT STEPS

The instrument developed in this study, Let's Get Healthy Together!, fills a gap in the literature, and provides OMR with a resource to begin to collect individual and aggregate health data while providing individual health education opportunities to adults with mental retardation and their families. The instrument should undergo further testing, but OMR can begin to collect aggregate data during the pilot testing process. The instrument should be a valuable complement to OMR's existing Health Risk Profile, a more clinically-oriented instrument which is used for those receiving residential services.

Pretesting procedures, consistent with established guidelines (National Bureau of the Census, 2003), were used in this study but should be repeated following the most recent modifications. The instrument should undergo pilot testing to verify reliability and validity. Finally, careful consideration needs to be given to the methods used to implement this instrument, including administration, assessment and the provision of feedback to the user.

6.3.1 Additional Pretesting

Pretest procedures consisted of expert reviews, followed by individual interviews with five caregivers who completed and returned the instrument, additional expert review, and analysis of errors and omissions among the returned surveys. Final changes that were made based on these steps should be submitted to another round of pretests with participants who were not involved in this study. **It is recommended that OMR consider devoting the time to conduct cognitive interviews with 15 participants**. This would consist of interviewing participants while they are completing the instrument, and obtaining immediate feedback. Participants can be asked to paraphrase certain questions, or to explain how they chose a particular response. Cognitive interviews with as few as 15 participants are considered by the Census Bureau to be sufficient for pre-field testing of an instrument. It is recommended, however, that in addition to the cognitive interviews, **OMR consult with additional experts to obtain further input into the instrument before conducting further testing**. Expert review is another established pretest procedure, and will serve as a useful supplement to the cognitive interviews.

6.3.2 Pilot Testing

Before adopting the instrument, **OMR should conduct pilot testing to assess reliability and validity**, which may result in further modifications. OMR's database should allow for the generation a random sample of parents of adults with mental retardation, along with their mailing information. An additional instrument can be included in the mailing for use in examining *criterion validity*. Another option is for OMR to use a measure in its own database, including the PUNS data, which prioritizes individuals for residential placement based on the urgency of need, to determine if those which rate at high risk on PUNS also have significant health risks on the Let's Get Healthy Together! instrument. *Construct validity* can be measured by analyzing responses on completed and returned surveys to determine if the expected relationships are evident. For example, people with Down Syndrome should report higher rates of heart defects from birth, and those who report taking medication for asthma or epilepsy should also report having been diagnosed with lung disease and epilepsy, respectively. Finally, OMR could choose to administer the instrument a second time to a subset of those who returned the survey, for the purpose of determining *test-retest reliability*.

OMR should also consider incorporating a respondent debriefing tool to assess user opinions on the instrument and their interpretations of specific questions. This could consist of a few questions added to the end of the instrument, or a supplemental sheet. It can be included for all participants, or for a sample. In addition, OMR can perform individual interviews, similar to the ones that were conducted in this study, with a sample of those who completed the survey.

6.3.3 Other Issues

OMR's ultimate goal is to implement the Let's Get Healthy! instrument in conjunction with a feedback mechanism. This means that after the user completes the survey, he/she would send it to a central location for data entry into a database that will have to be developed. The database would include programmed decision matrices in the form of queries that would determine the individual level of risk for each of the domain areas. The database could then be programmed to generate a report of all health risks, along with educational and resource information, which would be mailed to the user. A significant infrastructure will have to be created regardless of how this process is managed, and how the ISCs may be involved. The benefit of investing in implementing this system is that OMR can potentially influence individual health while obtaining population data from the returned surveys at the same time.

6.3.4 Conclusion

This project resulted in the development of a new caregiver-administered health assessment instrument for adults with mental retardation who live with their families. The instrument can be used on two levels: individually to identify health concerns and alert caregivers that an issue needs attention, and on a large scale to identify population based health issues that may merit public health intervention on a systemic level. It fills a gap in the literature, as no publicly-available instrument accomplishes both of these goals. Further testing of the instrument is recommended, along with exploration of the ancillary issues raised during the course of this study, and as noted earlier in this chapter.

APPENDIX A

FAMILY MEMBER FOCUS GROUP RECRUITMENT LETTER

Dear Potential Focus Group Participant;

Thank you for your interest in volunteering to participate in a focus group regarding the health of adults with mental retardation who live with their families. The study will involve developing a survey for you to complete that will assess the health of your family member. Health issues for adults with mental retardation have received increased attention in the last few years, but there is still a long way to go. Mental retardation is associated with increased prevalence of certain diseases, increased barriers in accessing health care, and increased mortality. Existing survey instruments are typically designed to be completed by a nurse, social worker, or residential staff person. The instrument that will be developed as a result of this study is important because there are no available instruments that are designed to be completed by a family member of an adult with mental retardation who lives with them.

You can contribute to this important project by attending a meeting where we will ask you to talk about health and your family member. You will be one of about 10 – 12 people to participate in a meeting that will last no more than two hours. The location and time will be announced at a later date, and will depend on the schedules and preferences of the volunteers. There will be no compensation for participants, but refreshments will be available.

Participation is voluntary, and there will be no consequences for participating or failing to participate. The meetings will be taped to facilitate analysis by the researcher, but there will be no personally identifying information maintained on any of the materials or notes. All comments will be held in confidence by the researcher.

The primary researcher and the focus group facilitator is a doctoral candidate at the University of Pittsburgh, Graduate School of Public Health, and a former staff member of several chapters of The Arc. This study is being conducted in cooperation with The Commonwealth of Pennsylvania, Office of Mental Retardation.

If you are interested in participating and are willing to receive a phone call about the study, please call The Arc at the phone number on the enclosed letter. I will call you to answer any questions that you have and to ask a few questions about you and your family member. If you are not interested, you don't have to take any action. If you decide you are interested in learning more about the study now, you can always decide not to participate later on.

Thank you very much for taking the time to read this and for your help in making this project a success.

Sincerely;

Nancy L. Klimon

APPENDIX B

FAMILY MEMBER SCREENING TOOL

I am calling you because I am doing a study in conjunction with (The Arc/OMR) and they told me that you might be willing to participate and that it was OK for me to call you.

[Explain Study]

Are you interested in participating in a group discussion about the health of people with mental retardation?

[If yes]: Skip to questions below.

[If no]. Another option is for me to speak with you personally, either in your home, in a public setting, or over the telephone.

[If yes]: I need to ask you a few questions [Skip to questions below].

[If no]: Thank you for your time and consideration.

I need to ask you some questions to decide what focus group to place you in. You don't have to answer these questions if you would prefer not to.

What is your:
Name
Address
Phone number
What is your gender?
What is your race?
What is your age?
Would you say you live in a rural area?
Are you the caregiver for an adult with MR who lives with you?
What is your relationship with this individual?
Are there others who live in the home?
What are their relationships with this individual?
Regarding your Family Member:
What is the age of your family member?
What is the level of MR of your family member? (Mild, Moderate, or Severe/Profound)
Is your family member ambulatory (can he/she walk?)
What is the gender of your family member?

APPENDIX C

PRE-FOCUS GROUP LETTER

Dear Focus Group Volunteer;

Thank you for volunteering to participate in a focus group regarding the health of adults with mental retardation who live with their families. I am enclosing another copy of the study overview that you may have received earlier. You can refer to that for a reminder about the purpose of the focus group and the study.

The focus group will be held on [date] at [location]. Directions are attached. We will be starting promptly at [time] and will finish no later than [time]. Refreshments will be available.

The meeting will consist of a facilitated group discussion of health for adults with mental retardation. You can participate as much or as little as you prefer. The meeting will be taped, but your responses will be held in confidence by this researcher.

The discussion will be guided by the following questions, although we may not get to all of these questions, and there may be additional questions that arise from the meeting.

What does health mean to you and your family member?
What concerns do you have about the health of your family member?
What are the barriers to your family member achieving good health outcomes?
What should an instrument measuring health look for?
What health issues are important to you?
What keeps your family member from being healthier?
[For younger adult focus group only]: What challenges did you face in helping your family member make the transition from pediatric to adult health care?

As noted earlier, there are no consequences for participation or for failure to participate. Your participation will help me to develop a survey instrument that is reflective of your opinions and concerns about the health of your family member.

Thanks again for your interest. If you have questions you can reach me at [insert]. I look forwarding to seeing you at [location] on [date/time].

Sincerely;

Nancy L. Klimon

APPENDIX D

FAMILY MEMBER PRE-INTERVIEW LETTER

Dear Study Volunteer;

Thank you for volunteering to participate in an interview regarding the health of adults with mental retardation who live with their families. I am enclosing an overview of the study. You can refer to this for a reminder about the purpose of the interview and the study.

The interview will be held on [date] at [location]. We will be starting promptly at [time] and will finish no later than [time].

Our conversation will be taped, but your responses will be held in confidence by this researcher.

Our discussion will be guided by the following questions, although we may not get to all of these questions, and there may be additional questions that arise from our meeting.

- What does health mean to you and your family member?
- What concerns do you have about the health of your family member?
- What are the barriers to your family member achieving good health outcomes?
- What should an instrument measuring health look for?
- What health issues are important to you?
- What keeps your family member from being healthier?
- What challenges did you face in helping your family member make the transition from pediatric to adult health care?

As noted earlier, there are no consequences for participation or for failure to participate. Your participation will help me to develop a survey instrument that is reflective of your opinions and concerns about the health of your family member.

Thanks again for your interest. If you have questions you can reach me at [insert]. I look forwarding to seeing you at [location] on [date/time].

Sincerely;

APPENDIX E

LITERATURE REVIEW: STUDIES IDENTIFYING HEALTH RISK FACTORS FOR ADULTS WITH MR

Table 4: Studies Identifying Health Risk Factors for Adults with Mental Retardation

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
Studies Conducted Outside of the United States					
(Beange, H., McElduff, A., & Baker, W., 1995)	202 Adults with MR in institution and community settings in Australia	Medical exams	Selection bias, limited generalizability	Increased obesity and hypertension associated with being female.	Weight/BMI,BP,amount of exercise, vision/hearing, epilepsy
(Center, J., Beange, H., & McElduff, A., 1998)	94 Individuals with MR in Sydney, AU, primarily living in community settings.	Clinical exam	Limited generalizability	Decreased bone mineral density. Risk factors - small body size, hypogonadism, low vitamin D levels, physical inactivity, DS.	Body size, presence of hypogonadism, presence of DS, vitamin D levels, vitamin taking, physical activity.
(Cooper, S. A., 1998)	134 People age 65 and older living in Leicestershire, UK. Comparison group of 73 randomly selected younger adults with mental retardation	Clinical assessment of individuals in community mental retardation registry in one community in the UK	Not a random sample. Clinical assessment conducted by the author. Comparison groups not matched for similar characteristics.	Increasing age associated with increased urinary incontinence, greater immobility, higher hearing impairment, increased prevalence of physical disorders. Younger age associated with greater prevalence of thyroid and dermatologic disorders.	Age
(Gabre, P., Martinsson, T., & Gahnberg, L., 2001)	124 Adults with ID, age 21 - 40	Longitudinal, clinical dental exams and x-rays given at hospital dental clinic	Conducted outside of US, Limited to those who attended a single, hospital-based, clinic.	More dental caries associated with mild ID and living in a community setting; Greatest loss of teeth associated with poor cooperation with dental care; Presence of DS associated with higher bone loss.	Level of MR, Cooperation with dental treatment, Presence of DS

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Lunsky, Y., 2003)	99 men and women with intellectual disabilities, with borderline to moderate MR in Ontario, Canada	Structured interviews with individuals, with information from caregivers and case documentation	No clinical verification of depression. Relied on self/caregiver report.	Women more likely to report depression, reported loneliness linked to higher depression scores.	Social activities, Relationships, Gender.
(Melville, C. A., Cooper, S. A., McGrother, C. W., Thorp, C. F., & Collacott, R., 2005)	247 adults with Down Syndrome matched with 247 adults with mental retardation but without Down Syndrome	Medical exams	Pairs not matched on level of mental retardation	Women with Down Syndrome more likely to be obese than those without Down Syndrome. Men with Down Syndrome more likely to be overweight but less likely to be obese than those without Down Syndrome.	Gender, Presence of Down Syndrome
(Morgan, C. L., Baxter, H., & Kerr, M. P., 2003)	1595 Individuals with learning disabilities (mental retardation)	Record linkage from various data sources and information registries in Wales.	Not generalizable	Increased age decreases risk of epilepsy compared to general population. MR and epilepsy together = increased inpatient and outpatient utilization, increased accident and emergency admissions, and increased fractures and soft tissue injuries. Mortality increases with epilepsy or MR	Presence of epilepsy, Inpatient utilization, Outpatient utilization, Hospital admissions for accidents and emergencies, Fractures, Injuries
(Patja, K., Molsa, P., & Iivanainen, M., 2001)	2369 Individuals with ID identified in large population-based study in 1962 and alive in 1963. Age 2 - 97	Prospective, 35 year study of mortality and contributing causes	Not generalizable	High risk of death from disease to age 30 associated with severe/profound ID, high risk of respiratory mortality from pneumonia associated with high level of ID	Presence of respiratory disease, level of MR, age

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Robertson, J. et al., 2000)	500 people with mental retardation living in various residential settings in the UK	Survey research	Based on staff report	Female gender, presence of Down Syndrome, and less severe MR linked to increased prevalence of obesity. More severe MR, increased age linked to greater inactivity. Less severe MR linked to increased likelihood of smoking.	Gender, Presence of Down Syndrome, Level of MR, Age.
(Taylor, N. S., Standen, P. J., Cutajar, P., Fox, D., & Wilson, D. N., 2004)	435 adults with mental retardation attending day programs in the UK	Interviews with the individual and/or proxy day program worker	Excluded those with less severe disabilities who were employed in the community. Use of worker as proxy.	Mild mental retardation linked to increased likelihood of smoking, and smoking more heavily.	Level of MR
(Tracy, J. & Hosken, R., 1997)	36 Adults with ID living independently in Victoria, Australia and registered with local govt entity; Selected for their independence in decision making.	Structured interview based on a questionnaire	Small sample size. Selection bias.	Smoking related to independence in decision making	Independence in decision making
Studies Conducted in Community Settings in the United States					
(Ailey, S. H., Miller, A. M., Heller, T., & Smith, E. V., Jr., 2006)	100 adults over the age of 30 with Down Syndrome	Secondary data analysis of self and caregiver report measures of depression, social support and life satisfaction	Secondary research. Limited to those over 30. Used self an caregiver report measures of depression.	Loneliness and social isolation linked to greater depression in adults with Down Syndrome.	Social activities and supports

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Braunschweig, C. L. et al., 2004)	48 adults with Down Syndrome living in community settings in Chicago	Questionnaires, weight, height, and waist measures, blood tests	Small sample size. Convenience sample.	Female gender related to higher BMI. Most obese or overweight, and none had adequate fruit/vegetable intake	Gender, BMI, intake of fruits and vegetables
(Eyman, R. K., Call, T. L., & White, J. F., 1991)	12543 Individuals with DS receiving services from state of CA from Mar 1984 to Oct 1987, and living in various residential settings	Review of CDER (annual 'Client Development Evaluation Report' used annually in CA for those in MR programs) and death reports	Not generalizable.	Lack of mobility or feeding skills better predictors of early death. Decreased level of intellectual functioning = increased mortality and increased likelihood of having co-morbidities.	Mobility, feeding skills, seizures, level of MR
(Friedman, JM, 2001)	Persons with Down Syndrome who died between 1968 and 1997	Analysis of CDC mortality data	Based on death certificates.	Black or other race linked to lower median age at death among those with Down Syndrome than whites with Down Syndrome.	Race
(Freedman, R. I. & Chassler, D., 2004)	629 Adults with MR living in various residential settings across state of Mass. In 2000	Random sample, administered Mass. DMR 'Consumer Survey Instrument'. Interviews with proxies	Use of proxy reporting. Limited to one state.	Individuals living with families less likely to have had a physical exam in the last year, a dental exam in the last 6 months, and, for females, to never have had a GYN exam	Frequency of physical exam, dental exam, GYN exam if female

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Fujiura, G. T., Fitzsimons, N., Marks, B., & Chicoine, B., 1997)	49 Individuals with DS (Down Syndrome) using 1 specialty clinic in a Chicago hospital and living at home with families	Administration of survey over phone combined with medical record review.	No sampling -- all volunteers. One single clinic. Only look at individuals with DS. Limited generalizability	Female related to greater chance of obesity. Lifestyle factors (friendship and social opportunity) best predictor of BMI, whereas diet and activity level were not predictors.	Secondary health conditions (# of), # meds used, weight/BMI, friendships, access to recreation and social opportunities, # close friends, # close relatives, # contacts, opportunity for friendships, opportunities for hobbies, access to recreational programs, # strenuous activities, independence
(Heller, T., Hsieh, K., & Rimmer, J., 2002)	44 adults with mental retardation age 30 and older and their caregivers in Chicago	Personal interviews with individual and survey of caregivers	Reliance on informant reports.	Expressed barriers to exercise: lack of transportation, cost, no on to show how to exercise, and inaccessible fitness centers	Availability of transportation, funds available, resources to help learn to exercise.
(Hsieh, K., Heller, T., & Miller, A. B., 2001)	268 adults with developmental disabilities age 30 and above living in nursing homes in Chicago	Interviews and direct observation	Limited to nursing homes.	Age over 70, ambulatory status and higher frequency of seizures linked to highest risk of injuries from falls. Maladaptive behavior and better overall health linked to non-fall related injuries	Age, mobility, seizure disorder, maladaptive behavior, overall health
(Hymowitz, N., Jaffe, F. E., Gupta, A., & Feuerman, M., 1997)	136 adults with mental retardation and mental illness	Unknown	Unknown	Mild or borderline MR, diagnosis of schizophrenia, linked to increased likelihood of smoking.	Level of MR, Diagnosis of schizophrenia

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Janicki, M. P. & Dalton, A. J., 2000)	4028 Day and residential settings in NY serving 41,807 persons age 40 and older	4 page questionnaires administered by facility administrators to those suspected of having dementia and returned to researchers.	Results not generalizable, facility decided to whom to administer survey.	Increased prevalence of dementia among adults with Down Syndrome.	Presence of Down Syndrome
(Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W., 1999)	2752 Individuals with ID, ago 40+, who died in NY state between 1984 and 1993, who were in programs associated with NY state	Review of database of state agency set up to track deaths of individuals with ID	Excluded individuals not in programs affiliated with NY state	Lower age at death, and lower for those with DS than those without. Earlier deaths for those in community and with families. Increased respiratory disease in older males. Increased cardiovascular disease in older females	Gender, Presence of DS
(Janicki, M. P. et al., 2002)	1600 Adults age 40 and older living in group homes in NY state	Testing of new health questionnaire	No data on non-responders. Convenience sample. Study was pilot test of instrument. Target population older adults.	Obesity (> 50%) Possible under-recognition of disease, due to significant difference between findings and NHANES date, Skin breakdown in those with lower intellectual functioning	Obesity, Skin breakdown, IQ

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Janicki, M. P. & Jacobson, John W, 1986)	10532 Older adults living in NY, in various settings including community residences and with families	Review of annual Developmental Disabilities Information System needs survey	Not a random sample. Results not generalizable.	Increased age associated with increased number of conditions, increased rates of cardiovascular, digestive, musculoskeletal, sensory and respiratory diseases. Community residents more likely to have cardiovascular conditions and less likely to have musculoskeletal, digestive and respiratory conditions. Greater intellectual impairment associated with higher incidence of musculoskeletal conditions, greater mobility impairment.	Age, level of intellectual impairment.
(Lerman, P, Apgar, D., & Jordon, T., 2003)	150 adults with mental retardation residing in New Jersey who left one institution, and 150 who remained.	Comparison of client assessment forms of movers vs, stayers.	Limited to one state.	Age, low self-care ability, medical conditions, and presence of seizure disorder are better predictors of early mortality than type of residence.	Age, self-care ability, presence of medical conditions, presence of seizure disorders.

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Minihan, P. M. & Dean, D. H., 1990)	333 Individuals with MR receiving services in community systems administered by Mass DMR/DMR in SE Mass	Questionnaire completed by service coordinator	Relied on report by service coordinators, used only individuals known to state	Lack of regular physician and living with family, lack of gyn exam in last 3 years for adult women, high prevalence of neuro, opthamaologicical, dermatological, psychological, musculoskeletal conditions. Ability to cooperate with medical exams and treatments a barrier to care. Inadequate home health care	Having 'regular' physicals, GYN exam in last 3 years for female, presence of neuro, opt, derm, psych, or musculoskeletal conditions, ability to cooperate with medical exams, perceived adequacy of home health care.
(Rimmer, J. H., Braddock, D., & Fujiura, G., 1993)	364 Adults age 17 - 72 living in 4 settings in large Midwestern state: institutions, ICF, group homes, and family	Percent of body fat with skin fold measurements; height and weight		Increased obesity associated with being female, having mild/moderate MR, living in a community setting (family or group home). Decreased control over environment related to decreased obesity.	Obesity, gender, level of MR, degree of control within environment
(Rimmer, J. H., Braddock, D., & Marks, B., 1995)	329 Individuals with MR living in various settings in 1 large Midwestern US state	Clinical labs, exams, and health behavior survey		Less restrictive settings associated with increased BMI and total cholesterol.	BMI, Cholesterol
(Rubin, S. S., Rimmer, J. H., Chicoine, B., Braddock, D., & McGuire, D. E., 1998)	283 Individuals with DS, age 15 - 69, who visited 1 clinic. 126 lived with family and 157 lived in group home	Medical record review	Generalizability, reliance on chart review.	Increased body weight and BMI significant for those living with family as opposed to group home.	Presence of DS
(Schupf, N. et al., 1998)	111 Adults with Down Syndrome age 30 – 70	Medical record review and semi-structured interview	Reliance on medical records for diagnosis of Alzheimer's disease	Male gender linked to earlier onset Alzheimer's	Gender

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Shavelle, R. & Strauss, D., 1999)	1812 Individuals with MR who left a CA state institution between April 1993 and Feb 1996	Review of CDER and CA mortality data	Not generalizable, use of previously institutionalized population.	Increased functioning related to increased mortality.	Level of functioning
(Strauss, D. & Eyman, R. K., 1996)	People with MR receiving services from CA DDS between Jan 1986 and Dec 1991	Analysis of CDER	Excludes those not receiving services. 1 state.	Highest mortality associated with those with DS after the age of 35	Presence of DS with age > 35
(Strauss, D., Kastner, T., & Shavelle, R., 1998)	22576 Adults receiving services in CA between 1985 and 1994, age 40+	Review of CDER	Limited to 1 state and only those age 40+	Increased mortality in community., and in all living settings when individual has poor mobility and poor self-help skills	Mobility, self-help skills
(Tyler, C. V., Jr., Snyder, C. W., & Zyzanski, S., 2000)	114 Adults age 40 – 60 who attended 2 sheltered workshops in Ohio	Osteoporosis screening	Limited sample, including those who lived in group homes.	Increased rate of osteoporotic bone mineral density related to presence of DS, limited mobility (use of cane, walker, or wheelchair), and African American.	Presence of DS, Mobility, Race

Table 4 (Continued)

Authors	Population Description	Methodology	Limitations	Health Risks ID'd	Potential Domains
(Wilber, N. et al., 2002)	656 Individuals with disabilities recruited from 6 independent living centers and 2 HMOs in Mass, >= 18 years old and able to provide informed consent. No proxy interviews.	Telephone (91%) and in-person interviews	Convenience sample. Limited to those able to give informed consent. Used self-report.	Overall high prevalence of secondary conditions, related to female gender , > 1 major disabling conditions, more ADL dependencies, more difficulty with ADLs, unmet need for mobility aids, tobacco use, marijuana use, difficulty maintaining weight, difficulty engaging in physical activity, experience of assault.	Presence of secondary conditions, gender, type of disability, activity limitations, health care access, tobacco use, independence in ADLs,

APPENDIX F

POTENTIAL INSTRUMENT DOMAINS, WITH ICF DOMAINS, SOURCES, POTENTIAL AND ACTUAL QUESTIONS

Table 5: Potential Instrument Domains, with ICF Domains, Sources, and Questions

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Age	Literature Review	Personal	Lower and older age linked to increased mortality	Age	8	Beange, 1995; Cooper, 1998, Janicki, 1986, Patja, 2001
Allergies	Individual Interviews	Body Function/Structures	--	Presence, Treatment	--	--
Cardiovascular	Individual Interviews, Literature Review	Body Function/Structures	Studies have shown high rates of undiagnosed hypertension and congenital heart disease. Increased cholesterol linked to greater independence in those with MR.	Presence of disorders, Treatment, Frequency of hospitalization.	14 E - M; 15 A - D; 23 A - C; 23G; 48 C - D	Beange, 1995, Rimmer, 1995
Care Coordination	Individual Interviews, Focus Groups, Expert Interviews	Environment	Family members frequently noted during interviews that ISCs are not helpful to them in improving the health of their family member.	Satisfaction, Access.	--	--

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Cues to Changing Health	Individual Interviews, Focus Groups	Participation	A change in any of these things can signal a health problem in someone who cannot communicate	Change in: Eating Habits, Sleeping Habits, Behavior, Ability to Perform Normal Activities. Increased attention on a particular body part.	13 A - B	--
Dementia	Literature Review, Expert Interviews	Body Function/Structures	Adults with Down Syndrome at increased risk of early onset Alzheimer's Disease	Change in memory and self-help skills.	16 A - C	Schupf, 1998; Bush, 2004
Dental	Individual Interviews, Focus Groups, Literature Review, Expert Interviews	Body Function/Structures, Participation	Increased prevalence of untreated dental disorders. Some studies show increased prevalence in adults who live with their families	Access to care, Tooth brushing, Flossing, Frequency of dental visits	38 A - B; 39; 40	Lifshitz, 2003, Cumella, 2000; Beange, 1995; Scott, 1998
Diet	Individual Interviews, Focus Groups, Literature Review	Participation	Increased prevalence of obesity. Decreased intake of fruits and vegetables.	Foods eaten, fruit/veggie intake.	30 A - B; 31 A - J; 32	Braunschweig, 2004;Robertson, 2000.

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Down Syndrome	Individual Interviews, Focus Groups, Literature Review	Body Function/Structures	Individuals with DS have greater mortality and morbidity	Presence of DS	14A	Gabre, 2001; Janicki, 1999
Epilepsy	Literature Review	Body Function/Structures	Higher prevalence of epilepsy than general population. Epilepsy linked to injury, increased health care utilization and increased rates of sudden death	Presence of Epilepsy	14C; 23F	Beange, 1995; VanAllen, 1999; Morgan, 2003
Exercise	Individual Interviews, Focus Groups, Literature Review	Participation	Regular exercise improves health and well-being. Inactivity linked to decreased bone mineral density.	Frequency of exercise, Duration, Level of Effort	33, 34	Fujiara, 1997; Center, 1998
Feeding Skills	Literature Review	Activities	Lack of feeding skills related to increased mortality.	Feeding skills.	26, 27	Eyman, 1991.
Gastrointestinal	Individual Interviews, Literature Review	Body Function/Structures	Individuals with CP, with lower IQ, males and with higher BMI are at greater risk for GI disorders	Diagnosis of GERD, Frequency of heartburn, reflux, intestinal disorders	23E; 26, 27	Janicki, 2002

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Gender	Literature Review	Personal	Female gender linked to obesity, increased hypertension, lower rates of exercise, GI disorders, depression. Male gender linked to respiratory disorders in old age.	Gender	10	Beange, 1995; Janicki, 1999; Lunsky, 2003; Melville, 2005; Rimmer 1993
Health Care Utilization	Individual Interviews, Literature Review	Participation	Research shows increased frequency of short hospital stays and physician visits. Utilization an indicator of increased morbidity and injury. Under-utilization of preventive screenings common.	# Physician visits, # Specialist visits, # ER visits, # Inpatient days. Use of preventive health screenings.	41 A - C; 42 - 47; 48 A - D; 49 A - E	Anderson, 2003; Davies, 2001; Havercamp, 2004; Minihan, 1990.

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Hearing	Literature Review	Body Function/Structures	Individuals with mental retardation found to have higher rates of sensory impairments, and they are frequently undiagnosed and untreated	Presence of disorders, Treatment, Access to Care	16E	Beange, 1995, Janicki, 2002
Independence in Decision Making	Literature Review	Activities	Increased independence linked to obesity and higher rates of smoking	Independence in decision making, Level of MR	--	Tracy, 1997.
Injuries	Literature Review, Expert Interviews	Participation	Increased risk of injury in those with seizure disorders, which are common in those with MR	Presence of seizure disorder	53 A - C; 54	Hsieh, 2001; Morgan, 2003
Level of MR	Literature Review	Body Function/Structures	Lower IQ linked to increased morbidity, mortality, musculoskeletal disorders, skin disorders, GI problems. Higher IQ linked to obesity.	Level of MR/IQ	12	Janicki, 2002; Robertson, 2000, O'Brien, 1991

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Medications	Literature Review, Expert Interviews	Participation	Psych meds can negatively impact health. Polypharmacy as issue in those with MR.	# of medications, communication between prescribing physicians.	20 - 22; 23 A - J	American Society of Consulting Pharmacists, 2006; Matson, 2004.
Mental Health	Individual Interviews, Focus Groups, Literature Review	Body Function/Structures	The prevalence of mental illness is believed to be higher in adults with mental retardation than the general population. Difficult to diagnose.	Depression, Anxiety, Mood, Behaviors, Access to treatment, Medications	14S; 23 H - I	NASMHPD, 2001; Reiss, 1977
Mobility	Literature Review	Activities	Limited mobility is related to increased morbidity and mortality in adults with mental retardation.	Mobility	17 A - D; 18; 19	Eyman, 1991; Strauss, 1998; Tyler, 2000.
Provider/Health System Related Issues	Individual Interviews, Focus Groups, Literature Review, Expert Interviews	Environment	Access to quality health care directly influences the health of individuals with MR	Satisfaction, Access, Preventive Focus, Communication (with individual and family), Aggressive approach to treatment, Stability, Knowledge	50; 51 A - C	Kastner, 1993

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Race	Literature Review	Personal	Increased mortality and increased likelihood of unmet health needs in non-Caucasians.	Race	11	Anderson, 2003; Friedman, 2001
Respiratory	Individual Interviews, Literature Review	Body Function/Structures	Respiratory-related mortality linked to decreased intellectual functioning	Presence of disorders, Treatment, Frequency of hospitalization	14T; 23D	Patja, 2001
Self-Help Skills	Literature Review	Activities	Increased mortality with decreased self-help skills	Independence with ADLs	16C	Strauss, 1998
Skin	Individual Interviews, Literature Review	Body Function/Structures	Studies have shown high rates of untreated skin disorders	Presence of disorders, Treatment	14 N - O	Janicki, 2002; Beange, 1995
Social/Recreational	Individual Interviews, Focus Groups, Literature Review	Environment, Participation	Social activities improve support systems, which enhance mental health and physical activity and health. Lack of access to recreational and social opportunities linked to obesity	Frequency of activity (social), Frequency w/o family involvement, # Friends, # Close Relatives, Frequency of Family Activity	9; 55 - 63	Ailey, 2006; Heller, 2002; Kastner, 1993; Fujiara, 1997

Table 5 (Continued)

Domain	Sources	ICF Domain	Significance	Potential Questions	Actual Questions	References
Sun Exposure	Literature Review, Expert Interviews	Participation	Risk of skin cancer as in general population	Skin protection habits, skin cancer screening	52 A - H	Ivry, 2006; Han, 2006
Tobacco Use	Literature Review, Expert Interviews	Participation	Some evidence of increased tobacco use in those with MR and mental illness	Tobacco use	35 - 37	Hymowitz, 1997; Taylor, 2004
Vision	Individual Interviews, Focus Groups, Literature Review	Body Function/Structures	Individuals with mental retardation found to have higher rates of sensory impairments, and they are frequently undiagnosed and untreated	Presence of disorders, Treatment, Access to Care	14R; 15E; 16D	Beange, 1995, Janicki, 2002; Warburg, 2002
Weight/BMI	Individual Interviews, Focus Groups, Literature Review, Expert Interviews	Body Function/Structures	Higher BMI linked to GI problems. Some studies show higher rates of obesity in adults with MR, particularly females	Weight, BMI, Food Choices	24 - 25	Braunschweig, 2004; Beange, 1995; Fujiura, 1997 Janicki, 2002

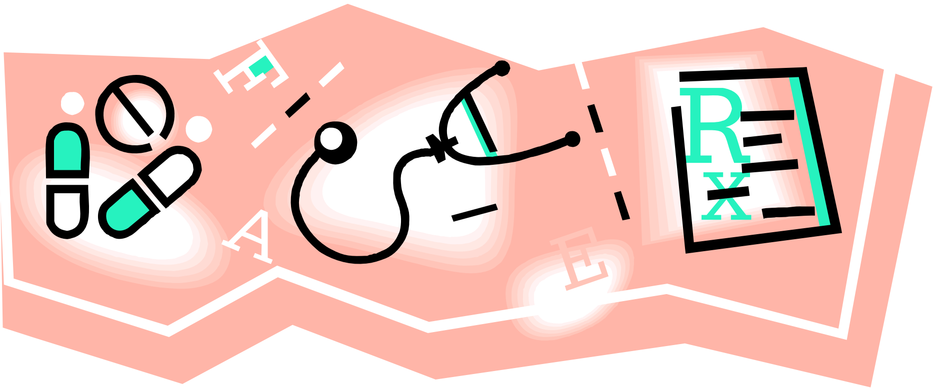
*** Questions Added (See Text): 1 - 7 (Administrative); 64 (Other); 14B (CP); 14D (Thyroid); 14 P - Q, 15 F - K (Cancer)**

NOTE: Some questions fall into more than one domain

APPENDIX G

LET’S GET HEALTHY TOGETHER HEALTH ASSESSMENT INSTRUMENT

Let’s Get Healthy Together!



A Health Assessment Instrument

The University of Pittsburgh
Graduate School of Public Health
Nancy L. Klimon
December 8, 2006

Let’s Get Healthy Together!

Instructions: The questions on these pages will help highlight any significant health risks for your family member with mental retardation. After you complete the questions, return this form to the Office of Mental Retardation at the address on the back page. You will receive, in the mail, a personalized report of the health risks that your family member may face. You should talk with your family member's primary care provider about any concerns that you have about his/her health. By completing this survey, you and your family member can Get Healthy Together!

NOTE: The term 'family member' in this survey refers to the adult person with mental retardation who resides with you, and for whom you are a caregiver.

Questions about You and Your Family Member

1) **What is today's date? ___/____/____**

2) **What is your name? ____**

3) **What is the first name of your family member? ____________________**

4) **What is your mailing address?____**

5) **What is your phone number? (   ) _____ - _________**

6) **What is your email address? ____**

7) **What is your date of birth? ____/____/____**

8) **What is your family member's date of birth? ____/____/____**

9) **How many total people reside in your home (Enter Number): _____________**

Let’s Get Healthy Together!

10) What is the gender of your family member?

Circle the number for your answer

Male	1
Female	2

11) What is the race of your family member?

Circle the number for your answer

White/Caucasian	1
Black/African American	2
Hispanic	3
Asian	4
Other	5

12) What level of mental retardation has your family member been diagnosed with? *Circle the number for your answer*

Mild (formerly known as EMR)	1
Moderate (formerly known as TMR)	2
Severe	3
Profound	4

13) How would you characterize your family member's overall health?

Circle number for your response for each question	**Excellent**	**Good**	**Fair**	**Poor**
A. Today?	1	2	3	4
B. 12 Months ago?	1	2	3	4

Questions about Conditions and Family History

14) Has your family member ever been diagnosed with any of the following?

Circle number for your response for each	**Yes**	**No**	**Not sure**
A) Down Syndrome	1	2	3
B) Cerebral Palsy	1	2	3
C) Epilepsy/Seizure Disorder	1	2	3
D) Thyroid Condition	1	2	3
E) Diabetes/Sugar Diabetes	1	2	3
F) High Blood Pressure/Hypertension	1	2	3
G) High Cholesterol	1	2	3
H) Heart Disease from a birth defect (fully corrected)	1	2	3
I) Heart Disease from a birth defect (partially corrected)	1	2	3
J) Heart Disease from a birth defect (not corrected)	1	2	3
K) Heart Attack	1	2	3
L) Congestive Heart Failure	1	2	3
M) Stroke	1	2	3
N) Chronic Skin Ulcers	1	2	3
O) Skin Rashes	1	2	3
P) Cancer: type: ______________________________	1	2	3
Q) Colon Polyps	1	2	3
R) Impaired Vision (wears glasses)	1	2	3
S) Depression	1	2	3
T) Lung Disease: type: _________________________	1	2	3
U) Undescended testicle (Skip to Question 15 if your family member is female	1	2	3

15) Has any close relative (mother, father, brother, sister, grandmother, grandfather) of your family member been diagnosed with any of the following?

Circle number for your response for each	**Yes**	**No**	**Not sure**
A) Diabetes/Sugar Diabetes	1	2	3
B) High Blood Pressure/Hypertension	1	2	3
C) High Cholesterol	1	2	3
D) Heart Disease	1	2	3
E) Glaucoma	1	2	3
F) Colon Polyps	1	2	3
G) Breast Cancer	1	2	3
H) Colon Cancer	1	2	3
I) Lung Cancer	1	2	3
J) Prostate Cancer	1	2	3
K) Testicular Cancer	1	2	3

16) In the last 12 months, have you noticed that your family member . . .

Circle number for your response for each	**Yes**	**No**	**Not sure**
A) Is becoming more forgetful?	1	2	3
B) Is less able to communicate?	1	2	3
C) Is having trouble performing his/her routine activities?	1	2	3
D) Doesn't see as well as he/she did a year ago?	1	2	3
E) Doesn't hear as well as he/she did a year ago?	1	2	3

Questions about Mobility

17) How often does your family member use any of the following to move from one place to the other?

Circle number for your response for each	**Never**	**Sometimes**	**Usually**	**Always**
A) Cane	1	3	4	6
B) Crutch or Crutches	1	3	4	6
C) Walker	1	3	4	6
D) Wheelchair	1	3	4	6

18) Has your family member's physical ability to move around changed in the last 12 months?

Circle the number for your answer

Yes 1

No *(Skip to Question 20)* 2

19) How has his/her physical ability to move around changed in the last 12 months?

Circle the number for your answer

He/she is moving around better..1

He/she is moving around with more difficulty...................................2

Questions about Medications

20) How many different medications does your family member take each day?

Circle the number for your answer

None (Skip to Question 24)	1
One (Skip to Question 23)	2
Two to Three	3
Four to Five	4
Six to Eight	5
Nine or More	6

21) Are these medications prescribed by different physicians?

Circle the number for your answer

Yes	1
No *(Skip to Question 23)*	2

22) Do the prescribing physicians know what is being prescribed by each other?

Circle the number for your answer

Yes	1
No	2
Not Sure	3

23) **Does your family member take medications for any of the following conditions?**

Circle the number for your answer for each	**Yes**	**No**	**Not Sure**
A) High Cholesterol	1	2	3
B) High Blood Pressure/Hypertension	1	2	3
C) Diabetes/Sugar Diabetes	1	2	3
D) Asthma	1	2	3
E) Stomach Disorder	1	2	3
F) Epilepsy/Seizure Disorder	1	2	3
G) Heart Disease	1	2	3
H) Depression	1	2	3
I) Other Psychiatric/Behavioral Condition *List other psychiatric medications here*:	1	2	3
J) Other Describe:	1	2	3

Questions about Nutrition, Exercise, and Smoking

24) **How tall is your family member?**

My family member is ________ feet and _______ inches tall

25) **How much does your family member weigh (in pounds)?**

My family member weighs: ___________ pounds

26) How does your family member eat?

Circle the number for your answer

By mouth, all of the time 1
By mouth and with tube feedings 2
By tube feedings, all of the time (Skip to Question 33) 3

27) How often does your family member have trouble swallowing foods?

Circle the number for your answer

Never 1
Sometimes 2
Usually 3
Always 4

28) Do <u>you</u> think your family member needs to lose weight?

Circle the number for your answer

Yes 1
No 2
Not Sure 3

29) Does <u>your family member</u> think he/she needs to lose weight?

Circle the number for your answer

Yes 1
No 2
Not Sure 3

30) On average, about how many servings of the following foods does your family member eat <u>each day</u>?

Circle number for your response for each	**None**	**1**	**2**	**3 or more**
A) Vegetables (not including potatoes)	1	2	3	4
B) Fruits (not including juice)	1	2	3	4

31) About how often does your family member usually eat the following foods? <u>(Not the low fat versions)</u>

Circle number for your response for each	**Never**	**Less than Once a Week**	**Once a Week**	**2-4 Times a Week**	**More than 4 times a Week**
A) Bacon or sausage	1	2	3	4	5
B) Beef or pork hot dogs	1	2	3	4	5
C) Hamburgers	1	2	3	4	5
D) Steak or beef	1	2	3	4	5
E) Ice cream	1	2	3	4	5
F) Cakes, cookies or crackers	1	2	3	4	5
G) Pizza	1	2	3	4	5
H) Butter or margarine	1	2	3	4	5
I) Mayonnaise	1	2	3	4	5
J) Salad dressing	1	2	3	4	5
K) Potato Chips	1	2	3	4	5
L) French Fries or other fried potatoes	1	2	3	4	5
M) Cheese	1	2	3	4	5
N) Milk	1	2	3	4	5

Let’s Get Healthy Together!

32) **Overall, about how often does your family member choose <u>low fat</u> versions of foods?**

Circle the number for your answer

Never	1
Sometimes	2
Usually	3
Always	4

33) **Does your family member exercise (enough to break a sweat) at least once a week?**

Circle the number for your answer

Yes	1
No (Skip to Question 35)	2

34) **On average, how many days of the week does he/she get 30 or more minutes of exercise that is vigorous enough to break a sweat?**

Circle the number for your answer

One day per week	2
Two to Three days per week	3
Four to Five days per week	5
Six to Seven days per week	6

35) **Does your family member smoke cigarettes?**

Circle the number for your answer

Yes	1
No (Skip to Question 37)	2

36) **How many packs of cigarettes does your family member smoke each week?**

He/She smokes _________ packs of cigarettes each week

37) Does your family member regularly spend time in rooms where other people are smoking?

Circle the number for your answer

Yes 1
No 2

Questions about Oral Health

38) Does your family member:

Circle number for your answer for each question	**Yes**	**No**	**NA (No Teeth)**
A) Brush, or get his/her teeth brushed, at least daily	1	2	4
B) Floss, or get his/her teeth flossed, at least daily	1	2	4

39) How often does your family member see the dentist?

Circle number for your answer for each question

Never 1
Every 3 or more years 2
Every 2 years 3
Every year 4
At least twice each year 5

40) When it comes to paying for your family member’s dental care, about how often:

Circle number for your answer for each question	**Never**	**Sometimes**	**Usually**	**Always**
A) Do you pay for his/her dental care out-of-pocket?	1	2	3	4
B) Do you use Medicaid to pay for his/her dental care?	1	2	3	4
C) Do you use some other insurance pay for his/her dental care?	1	2	3	4

Questions about Exams, Doctor Visits and Screenings

41) Has your female family member ever… (Skip to Question 45 if Family Member is Male)

Circle number for your answer for each question	**YES**	**NO**	**Not Sure**
A) Had a mammogram?	1	2	3
B) Had a pap smear?	1	2	3
C) Had a bone-density screening?	1	2	3

42) Did your family member first start her period before she turned 12 years old?

Circle the number for your answer

Yes	1
No	2
Not Sure	3

43) Has your family member started menopause (change of life)?

Circle the number for your answer

Yes	1
No	2
Not Sure	3

44) Does your family member perform self-breast exams at home?

Circle the number for your answer

Yes	1
No	2
Not Sure	3

45) Has your male family member ever been screened for prostate cancer? (Skip to Question 48 if Family Member is Female)

Circle the number for your answer

Yes	1
No	2
Not Sure	3

46) Has your male family member ever been screened for testicular cancer?

Circle the number for your answer

Yes	1
No	2
Not Sure	3

47) Does your male family member get testicular exams at home?

Circle the number for your answer

Yes	1
No	2
Not Sure	3

48) Has your family member ever received…

Circle number for your answer for each question	**YES**	**NO**	**Not Sure**
A) A test for blood in stool?	1	2	3
B) An exam to look at the inside of his/her colon?	1	2	3
C) A blood test for diabetes (sugar diabetes)?	1	2	3
D) A blood test for high cholesterol?	1	2	3

Let’s Get Healthy Together!

49) How many times <u>in the past 12 months</u> has your family member:

Circle number for your answer for each	**None**	**1 - 3 times**	**4 - 6 times**	**7 or more times**
A) Had an appointment with his/her <u>primary care provider</u>?	1	2	3	4
B) Had an appointment with a <u>specialist</u> who is not his/her primary care provider?	1	2	3	4
C) Visited the emergency room for an <u>illness</u>?	1	2	3	4
D) Visited the emergency room for an <u>injury</u>?	1	2	3	4
E) Been <u>hospitalized</u> at least overnight?	1	2	3	4

50) Does your family member have any of the following to pay for his/her health care costs?

Circle number for your answer for each question	**YES**	**NO**	**Not Sure**
A) Medicaid (Access Card or HealthChoices)	1	2	3
B) Medicare	1	2	3
D) Other health insurance	1	2	3

51) Is your family member in a managed care plan (HMO) for his/her health insurance?

Circle the number for your answer

Yes 1
No...2
Not Sure 3

Questions about Sun Exposure

52) Does your family member:

Circle number for your answer for each question	**YES**	**NO**	**Not Sure**
A) Have a large number of moles?	1	2	3
B) Get freckles after being in the sun?	1	2	3
C) Have a history of at least one severe, blistering sunburn as a child or teenager?	1	2	3
D) Wear sunglasses when out in the sun?	1	2	3
E) Have skin that burns easily?	1	2	3
F) Wear sunscreen when out in the sun for prolonged periods of time?	1	2	3
G) Spend a lot of time outside?	1	2	3
H) Check, or have someone check, his/her skin regularly for changes in moles?	1	2	3

Questions about Safety

53) Does your family member:

Circle number for your answer for each question	**YES**	**NO**	**Not Sure**	**N/A**
A) Always use seatbelts when in a motor vehicle?	1	2	3	4
B) Always use a helmet when riding a bicycle	1	2	3	4
C) Ride in vehicles where someone drinks and drives?	1	2	3	4

54) Does your home have a working smoke detector?

Circle the number for your answer

Yes 1

No..2

Questions about Social Relationships

55) Not including you and any other family members who reside with you, how many <u>relatives</u> does *your family member* see or hear from at least once a month?

Circle the number for your answer

None	1
One	2
Two	3
Three or Four	4
Five or More	5

56) Not including you or anyone else who lives with you, how often does your family member see or hear from the <u>relative</u> with whom he/she has the most contact?

Circle the number for your answer

Never	1
Seldom	2
Sometimes	3
Often	4
Very Often	5
Always	6

57) How many <u>relatives</u> can your family member call on for help, if necessary?

Circle the number for your answer

None	1
One	2
Two	3
Three or Four	4
Five or More	5

58) How many neighbors does your family member see or hear from at least once a month?

Circle the number for your answer

None	1
One	2
Two	3
Three or Four	4
Five or More	5

59) How often does your family member see or hear from the neighbor with whom he/she has the most contact?

Circle the number for your answer

Never	1
Seldom	2
Sometimes	3
Often	4
Very Often	5
Always	6

60) How many neighbors can your family member call on for help, if necessary?

Circle the number for your answer

None	1
One	2
Two	3
Three or Four	4
Five or More	5

61) How many friends, who are not also neighbors or relatives, does your family member see or hear from at least once a month?

Circle the number for your answer

None	1
One	2
Two	3
Three or Four	4
Five or More	5

62) How often does your family member see or hear from the friend with whom he/she has the most contact?

Circle the number for your answer

Never	1
Seldom	2
Sometimes	3
Often	4
Very Often	5
Always	6

63) How many friends can your family member call on for help, if necessary?

Circle the number for your answer

None	1
One	2
Two	3
Three or Four	4
Five or More	5

64) Do you have any comments?

THANK YOU!

Please send your completed survey to:

xxxxxxxxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxxxxxxxx

Your responses will be reviewed and analyzed, and you will receive a personalized report of the health risks your family member may face, and the steps you can take to improve his/her health.

APPENDIX H

PRETEST QUESTIONNAIRE

Let’s Get Healthy Together!
PreTest Questionnaire
October 9, 2006

PreTest Participant (First Name, Last Initial): ____________________
Date Conducted: ____

1) About how long (in minutes) did it take for you to complete the instrument?

____

2) What did you think about how long it took you to complete?

___ Took too long to complete

___ Took just the right amount of time to complete

___ Didn’t take long enough

3) What did you think about the number of questions?

___ Too many questions

___ Just the right number of questions

___ Not enough questions

4a) You received two versions – a small booklet and a large booklet – with the same questions. Which version would you prefer to use?

___ Small Size Booklet

___ Large Size Booklet

4b) Why?: ____

5a) Sometimes people skip over the instructions and go right to the questions. Did you read the instructions?

____ Yes

____ No (SKIP TO 6a)

5b) If yes, did you understand the instructions on page 1?

____ Yes

____ No

5c) What did you find confusing about the instructions?

____

____

Now I am going to ask you about the questions themselves.

Questions 1 – 10 ask about where you live, your age, your family member's age and gender, and how many people reside in your home.

6a) Were any of these questions unclear?

___ Yes
___ No (SKIP TO 7a)

6b) If yes, which one (s)? ____

6c) Why was it unclear? ____

6d) How would you improve it? ____
____
____

7a) Were you uncomfortable answering any of them?

___ Yes
___ No (SKIP TO 8a)

7b) If yes, which one (s)? ____

7c) What made you uncomfortable? ____

7d) How would you improve it? ____
____
____

8a) Question 11 asks about the race of your family member. Were you comfortable answering this question?

___ Yes
___ No

This question was included because some people are at higher risk for certain diseases due to their race. For example, white women have higher risk of osteoporosis than black women. Blacks with Down Syndrome have shorter life spans than whites with Down Syndrome.

8b) Do you think people would be more comfortable answering this question if there was an explanation about these different health risks due to race?

___ Yes
___ No

9a) Question 12 asked about the level of mental retardation of your family member. Do you think the other parents that you know are aware of this for their family member?

___ Yes
___ No

9b) Do you think people would be better able to answer the question if I added the IQ range for each level?

___ Yes
___ No

9c) Do you have any suggestions for improving this question?

____
____
____

9d) Question 14 asks about the conditions your family member has been diagnosed with. Did you understand how to complete this question?

___ Yes
___ No

10a) Do you think the word 'elevated' should be replaced with 'high'?

___ Yes
___ No

10b) Do you think most people understand what heart disease means?

____
____
____

10c) Do you have any comments about this question?

____
____

11a) Question 16 asks about how your family member moves around. Did you understand this question when you first read it?

___ Yes
___ No (Skip to 12a)

11b) In what way was it confusing?

____
____
____

11c) What suggestions do you have to re-word it?

____
____
____

12a) Question 21 asks about the medications your family member takes. Do you think most people who use this survey will know what the word ‘gastrointestinal’ means?

___ Yes
___ No

12b) Was anything confusing about this question?

____
____
____

12c) Do you have any suggestions for improving it?

____
____
____

13a) Question 23 asks about how your family member’s physicians communicate with each other about the different medicines he/she takes. Did you understand how to answer this question?

___ Yes
___ No

13b) Was anything confusing about this question?

____

____
____

13c) Do you have any suggestions for improving it?

____
____
____

14a) Questions 30 – 33 ask about the foods your family member eats.

14b) Would it be helpful if questions 30a and 30b explained what a serving size meant? Like 1 serving of fruit = 1 medium apple.

___ Yes
___ No

14c) What foods would someone eat if they had a medium fat diet? (Q 31)

____
____
____

14d) Questions 32 and 33 ask how often family members eat higher fat meats. Do you think most people will be comfortable answering this question?

___ Yes
___ No (SKIP to 15a)

14e) If no, why not?

____
____
____

14f) How would you revise this question to make it more likely that people will answer it?

____
____
____

15a) Questions 34 and 35 ask how often your family member exercises. Did you understand how to answer these questions?

___ Yes
___ No (SKIP to 16a)

15b) If no, why not?

____

15c) How would you revise this question?

16a) Question 41 asks who pays for your family member's dental treatment. Do you think most people would be comfortable answering this question?

___ Yes
___ No (SKIP to 17a)

16b) If no, why not?

16c) How would you revise this question to make it more likely that people will answer it?

Questions 42 to 47 ask about gender-specific cancer screening tests.

17a) SKIP IF FAMILY MEMBER IS MALE: If the survey asked if your female family member performs breast self-exams at home, would you be able to answer that?

___ Yes
___ No

17b) SKIP IF FAMILY MEMBER IS FEMALE: Were you comfortable answering question 47 about self testicular exams at home?

___ Yes
___ No

18a) Questions 51 and 52 ask about insurance. Do you think most people will be comfortable answering these questions?

___ Yes
___ No (SKIP TO 19a)

18b) If no, why not?

18c) How would you revise this question to make it more likely that people will answer it?

19a) Question 53 asks about Sun Exposure. Were you able to answer these questions without difficulty?

___ Yes
___ No (SKIP to 19d)

19b) If no, why not?

19c) How would you revise this question?

19d) What does 'regular skin cancer screenings' mean to you?

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