

KidneyWorks

A Job Retention Program for People with *Chronic Kidney Disease* (CKD)

By the American Association of Kidney Patients (AAKP) and
The Medical Education Institute (MEI)



“Whoever has the most definitive voice with the patient, whether it’s the doctor, the nurse, the social worker or somebody in their community or who they work with can have a profound influence on their aspirations. Everyone has an aspiration if you take the time to learn it.”

Paul Conway

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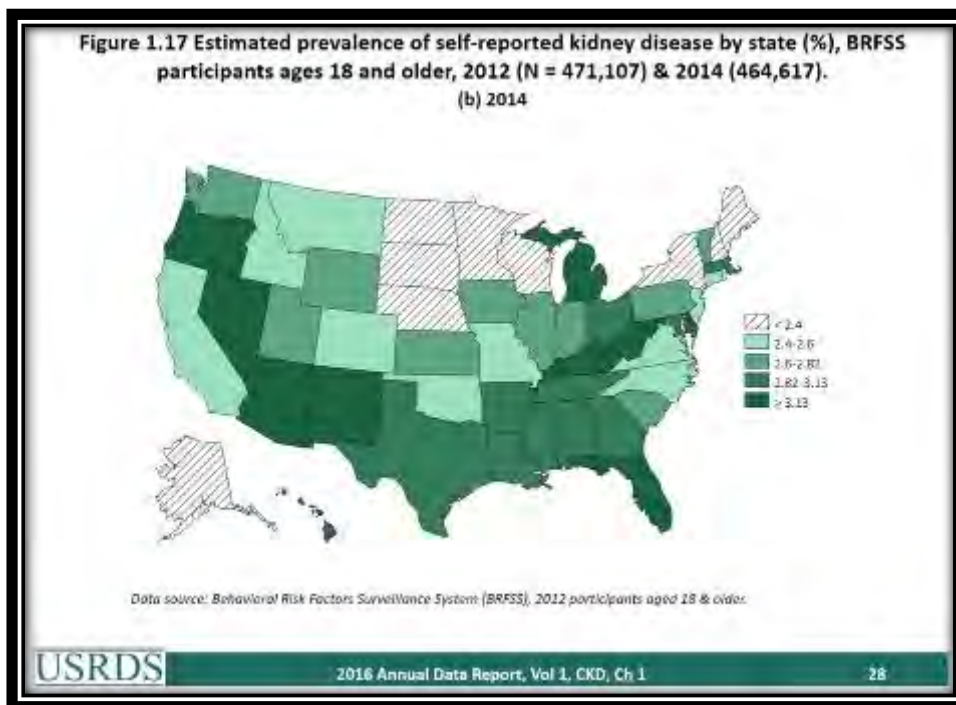
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Executive Summary

Employment Challenges Facing People with CKD

The American Association of Kidney Patients (AAKP) and the Medical Education Institute (MEI), two non-profit kidney organizations, are spearheading **KidneyWorks™** a collaborative effort to **keep CKD patients employed, slow progression of kidney disease, and help working Americans avoid a life on disability**. In June, 2016, a team of expert stakeholders from all sectors of the kidney community—patients, non-profits, professionals, members of industry and representatives from the Federal government—met in Washington, D.C. to address challenges facing employed people with CKD who may be at risk for kidney failure, and discuss strategies to help them keep their jobs and their dignity. This summary reports their conclusions.

In the U.S., more than 20 million adults are estimated to have Stage 1-5 **chronic kidney disease** (CKD), which can lead to **kidney failure (end-stage renal disease, ESRD)**. People whose kidneys fail require dialysis or a kidney transplant to survive. KidneyWorks focuses on Americans with CKD whose kidneys have *not yet failed*, or *non-dialysis chronic kidney disease* (ND-CKD). While total costs for all ND-CKD patients are difficult to obtain, the **Medicare-only costs in 2014 for ND-CKD exceeded \$58B per year**—and these include only those who are over age 65 or already disabled.



In 2010, 13.2% of the U.S. population aged 30 or older had CKD, a figure that is projected to rise to 14.4% in 2020 and to 16.7% in 2030. The map above shows an estimate of how many American adults had been told by a doctor, nurse, or other healthcare professional that they have kidney disease (from the CDC's 2014 Behavioral Risk Factor Surveillance System questionnaire).

For the 53% of people with CKD who are working-age, keeping a job helps ensure access to preventive care they desperately need to delay or avoid kidney failure—and remain active, productive, tax-paying citizens. Working creates routines and boosts self-esteem, income, feelings of purpose, and social interaction. CKD symptoms can pose challenges for keeping a job—but, most of these symptoms can be effectively treated. Children who have kidney disease need to remain in school so they can be productive when they become adults.

Many working-age people with CKD *do* work—but many lose their jobs. **Between 2006 and 2014, 68,341 people with CKD lost their jobs in the 6 months before they developed ESRD.** Yet, it seems reasonable to expect that continued employment of people with CKD can:

- Improve people’s health, quality of life, and survival—and prevent disability
- Protect income and health benefits and offer as normal a lifestyle as possible
- Reduce costs to Medicare, Medicaid, and federal and state support programs
- Help employers lower their costs by retaining valued and skilled employees
- Keep private health insurers’ members healthier through preventive care
- Lower expenditures for private disability insurers

For many Americans, employment gives life a sense of *purpose*. And, while all those with CKD expend time and money to treat their illness, not being able to work due to CKD has costs such as:

- Lower lifetime income and retirement earnings and savings
- Unplanned life decisions and deferrals of major decisions such as home purchases
- Fear, anxiety, and stress on family and loved ones
- Loss of relationships and friendships, and sense of identity

Societal costs of preventable dependency and disability for those with ND-CKD include:

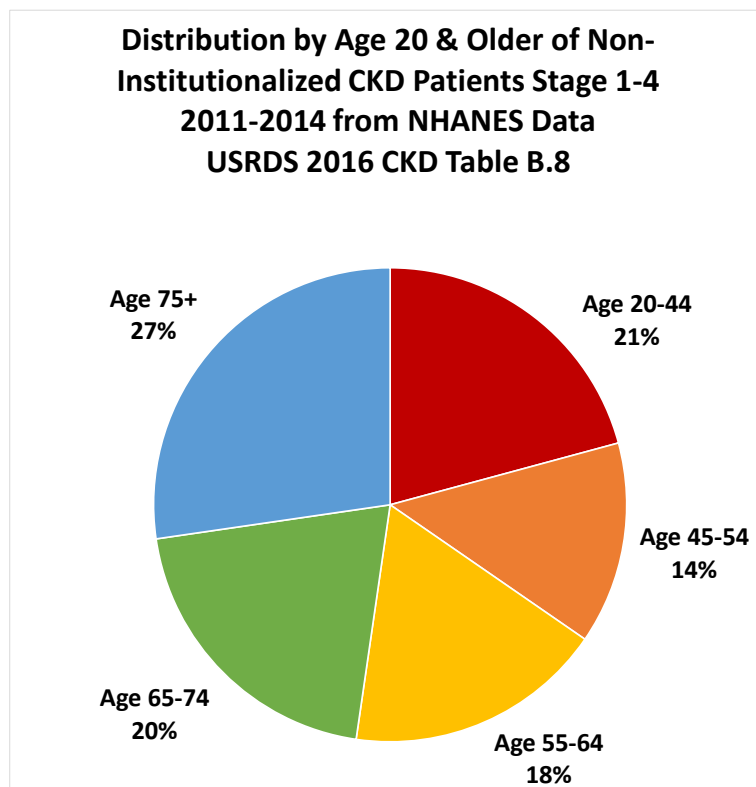
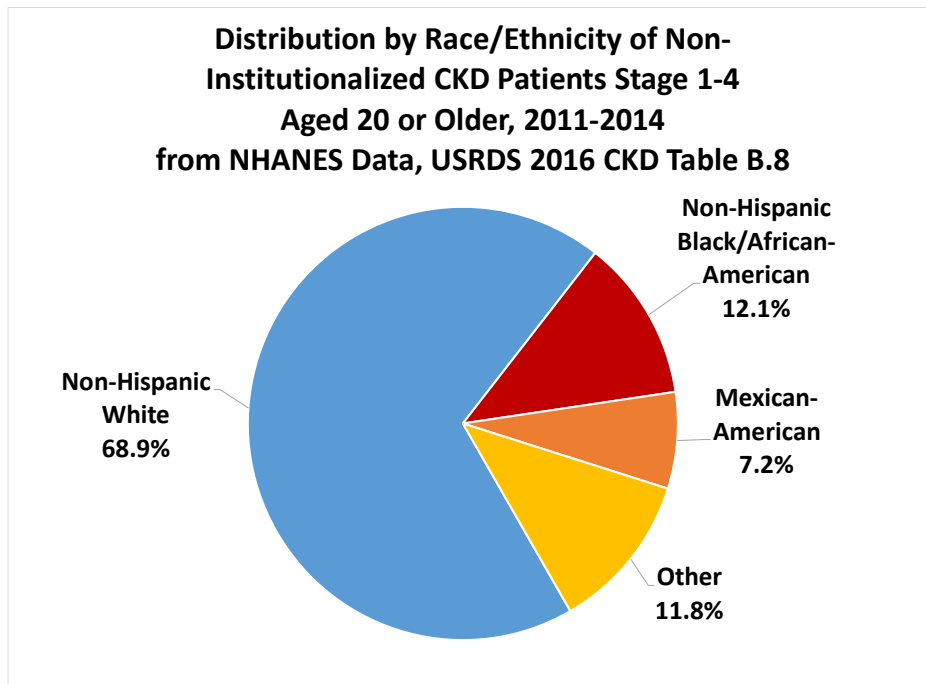
- Lost federal and state tax revenue
- Reduced workforce productivity and GDP
- Greater healthcare expenditures for both patients themselves and taxpayers
- Increased federal spending for disability, Medicare, and Medicaid

Barriers to CKD employment identified by the KidneyWorks stakeholder group:

- Patients may believe that disability is an attractive option
- Healthcare providers may believe that patients cannot or do not want to work
- Patients may not know their workers’ rights and when/how to talk with an employer about CKD
- Patients may fear discrimination and have concerns about coworkers perceiving preferential treatment
- Lack of education among some patients and medical professionals not in the kidney community about how to slow kidney disease
- Children’s schools may not fully support their attendance with a chronic illness
- Patients may receive mixed messages from family and friends about continuing to work
- Patients may feel overwhelmed by life changes and the unpredictability of chronic illness
- Patients may have work-limiting symptoms such as fatigue, weakness, and cognitive dysfunction (“brain fog”)

The two leading causes of chronic kidney disease are type 2 diabetes and high blood pressure. While CKD and kidney failure can be devastating for anyone, the impact on **American minority adults**, who are

at disproportionately higher risk for CKD and kidney failure than whites compared to their prevalence in the population, is even *more* alarming.



KidneyWorks Recommendations

In response to these barriers, KidneyWorks expert stakeholders made five core recommendations, as well as specific recommendations to several key audiences:

- 1. Raise awareness of CKD among the general public and those most at risk.** Use creative approaches to target employers, organizations, clinicians, patients and families with key messages.
- 2. Identify CKD early and provide optimal medical and psychosocial management.** Screen those at higher risk and use a team approach to empower patients and families to self-manage, share decision-making, and make lifestyle changes such as exercise that can help slow disease progression.
- 3. As soon as CKD is diagnosed, provide patients and family members with employment-supportive education.** To continue working, patients must learn to self-manage CKD, understand their rights on the job, and obtain job support. Education can help patients plan a treatment for kidney failure, should that occur, that allows them to work, such as transplant or home dialysis. Identify opportunities for education from early CKD to dialysis and transplant, with the assistance of agencies such as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the Health Resources and Services Administration (HRSA), and the National Kidney Disease Education Program (NKDEP) clearinghouse. Tailor information to their needs and offer it in a variety of formats—early and often.
- 4. Take active steps to slow CKD progression.** Help patients learn how to control blood pressure and blood sugar control, to exercise, lose weight, limit dietary protein, quit smoking, and learn symptoms to watch for and report.
- 5. Support kidney transplant recipients in the workforce.** After a transplant, encouraging continued work, identifying meaningful work that creates a sense of purpose, encouraging employer flexibility, and offering vocational support are proven interventions to help people stay in the workforce.

For Patients:

- Those with known CKD should ask their primary care physician for a referral to a nephrologist; seek out CKD education, support, and resources; and participate in and follow their treatment plans.
- Those who do not know if they have CKD should ask for copies of laboratory test results, track them over time, and ask about any high or low results.

For Employers:

- Allow flex-time or time off for medical appointments to promote better employee health.
- Retain employees who have CKD to avoid the high costs of hiring and training new employees, many of whom will *also* have one or more chronic illnesses—as half of all Americans do.

For Medical/Professional Societies:

- Consider developing performance measures to support patient employment throughout CKD.
- Examine models used by other countries that maintain patient employment despite advancing CKD or other chronic illnesses, and determine whether those models can be used or adapted for the U.S.
- Increase nephrology fellows' awareness of the challenges faced by employed patients—and the many benefits to patients and their families—and society—of continuing to work with ND-CKD.

For Healthcare Providers:

- Offer appointment times that accommodate patients' work schedules.
- Talk with patients and families about the benefits of working and avoiding disability when possible.
- Remember that patients who can keep their jobs are more likely to retain employer group health plans that will bring in more revenue to a practice or clinic than Medicare or Medicaid.
- Consider the societal benefits of a healthier population with fewer hospitalizations, less anxiety and depression, and a more active lifestyle.

For Policymakers/Congress:

- Recommend that government and private health plans cover early CKD screening of those who are at increased risk of progression according to KDIGO guidelines.
- Encourage insurance companies, providers, and businesses to make it financially feasible to hire and retain employees with chronic illnesses, including ND-CKD.
- Promote training for vocational rehabilitation counselors, social workers, and physicians that includes education about the unique needs of CKD patients who want to keep their jobs.
- Provide tax credits for employers of *any* size to make accommodations, including telework when feasible, for those with chronic illnesses and disabilities.
- Develop a national education campaign for employers and employees to explain the Americans with Disabilities Act and the Family and Medical Leave Act, and to debunk myths about hiring and retaining employees with a chronic illness.
- Consider amending the Medicare Improvements for Patients and Providers Act (MIPPA) to expand qualified CKD education providers to include clinical social workers and add employment as a topic.
- Expand MIPPA Kidney Disease Education (KDE) Services to include any Medicare patient diagnosed with CKD, not just Stage 4.
- Study the feasibility of expanding the Family Medical and Leave Act to additional employers and encouraging employers to continue to pay workers during a medical leave of absence.

For Other Federal Agencies:

- **Centers for Disease Control and Prevention (CDC):**
 - Expand the Kidney Disease Initiative to include a public outreach campaign coordinating with the Public Health Services.
 - Study geographic disparities in the prevalence and incidence of both CKD and ESRD.
- **Centers for Medicare & Medicaid Services (CMS):**
 - Collect data on employment up to 5 years prior to ESRD and include the *type* of job (e.g., sedentary, active, mixed) on Form CMS-2728 (ESRD Medical Evidence Report).
 - Reimburse physicians, non-physician providers, and CKD healthcare teams to discuss goals, employment benefits, and barriers with their patients and work together to overcome them.
 - Provide sufficient reimbursement to motivate registered dietitians and clinical social workers to become Medicare providers so they can be reimbursed to see ND-CKD patients prior to ESRD.
 - Include in the USRDS contract a study of the barriers to utilization of Medicare's Kidney Disease Education Services.
- **National Institutes of Health (NIH):** Designate funding to support CKD research projects that include employment as a variable.
- **Department of Labor (DOL):** Provide evidence-based early intervention services to working people with stable CKD, including transplant recipients.

- **Rehabilitation Services Administration (RSA):** Study what is needed (services and/or equipment) to help state vocational rehabilitation agencies help people with ND-CKD keep their jobs.

KidneyWorks next steps are to:

- Identify funding support from industry
- Develop outreach materials and messaging
- Collaborate with other chronic disease organizations to boost employment
- Develop a business case for employers
- Include employment as a topic in professional clinical curricula/continuing education
- Create a patient website and toolkit
- Develop pilot projects

Conclusion

Kidney disease is both costly and devastating, but non-dialysis chronic kidney disease (ND-CKD) does *not* have to mean permanent disability. Working-age Americans who are diagnosed with CKD can have far greater independence to pursue their aspirations, achieve better health outcomes and contribute more fully to their families and society if they are able to slow the progression of their disease and stay employed. ***Barriers to their desire and ability to keep working must be identified and removed.***

KidneyWorks seeks to reduce disability and dependency and help people with ND-CKD remain active, productive, taxpaying citizens by taking proactive steps to educate patients, families, clinicians, and lawmakers and enact work-friendly practices and policies. **ND-CKD patients who continue to work help themselves, their families, their healthcare providers, the healthcare industry in general, insurers, employers, taxpayers—and the U.S. government.**

Everyone Benefits When Kidney Patients Keep Working

Who Benefits?	What Are Advantages of CKD Patient Employment?
Patients	<ul style="list-style-type: none"> ■ Higher income compared to disability ■ Better adaptation to kidney disease ■ Better access to health insurance (sometimes provided by the employer) ■ Better health, better quality of life and lower rates of depression ■ Greater independence
Family members	<ul style="list-style-type: none"> ■ More normal lifestyle, financially and otherwise
Taxpayers	<ul style="list-style-type: none"> ■ Extending the life of the Social Security Disability Trust Fund and Medicare <ul style="list-style-type: none"> ➢ In 2017 dollars, each worker who retains his/her job instead of applying for disability saves the trust fund \$14,052 a year on average. ➢ In 2014, Medicare spent \$22,745 on average for a ND-CKD patient and \$78,934 for an ESRD patient. Medicare can save more than \$56,000 each year for each person who does not progress to ESRD. Cost savings to commercial insurers are likely much higher, as they bill at a higher rate than Medicare.
Federal, state and local government	<ul style="list-style-type: none"> ■ Fewer people receiving welfare and/or disability benefits ■ Lower Medicare and Medicaid costs ■ Increased tax revenues

Who Benefits?	What Are Advantages of CKD Patient Employment?
Employers	<ul style="list-style-type: none"> ■ Savings associated with not needing to recruit and train a new employee ■ Tax credits and deductions for workplace accommodations ■ Compliance with federal and state laws
Providers	<ul style="list-style-type: none"> ■ Higher revenues from commercial insurers than Medicare or Medicaid if patients begin dialysis ■ Improved staff morale when patients are healthier and less depressed
Health industry	<ul style="list-style-type: none"> ■ Increased demand for technology, innovation, products and services that enhance patients' ability to work
Insurers	<ul style="list-style-type: none"> ■ Healthier members with preventive care and, thus, lower expenditures

The table below shows the data by state of the number of people with *kidney failure* and the average Medicare costs per patient by state in 2014. **Keeping patients working would save federal, state, and local governments money in healthcare costs and provide economic benefits.**

Medicare Spending (\$) Per ESRD Prevalent Patient by State 2014

State	ESRD Prevalent Patients	Medicare Primary Spending/Person
Alabama	9,570	\$67,262
Alaska	644	\$75,768
Arizona	8,050	\$70,246
Arkansas	4,600	\$66,510
California	49,877	\$88,577
Colorado	4,294	\$65,604
Connecticut	4,539	\$87,753
Delaware	1,969	\$79,164
District of Columbia	1,830	\$87,433
Florida	29,019	\$80,441
Georgia	19,051	\$75,554
Hawaii	2,229	\$71,304
Idaho	1,556	\$66,733
Illinois	22,413	\$85,741
Indiana	10,208	\$79,102
Iowa	3,806	\$64,058
Kansas	3,653	\$68,303
Kentucky	6,119	\$75,556
Louisiana	9,613	\$75,710
Maine	1,406	\$68,534
Maryland	11,157	\$89,376
Massachusetts	7,338	\$93,116
Michigan	16,376	\$82,004
Minnesota	4,785	\$70,762
Mississippi	7,893	\$68,701
Missouri	9,419	\$72,282
Montana	1,095	\$58,101
Nebraska	2,159	\$67,833

State	ESRD Prevalent Patients	Medicare Primary Spending/Person
Nevada	3,514	\$79,458
New Hampshire	1,208	\$73,525
New Jersey	15,201	\$96,746
New Mexico	3,432	\$60,822
New York	26,686	\$90,803
North Carolina	17,528	\$69,246
North Dakota	893	\$60,483
Ohio	16,763	\$82,168
Oklahoma	5,913	\$69,044
Oregon	3,730	\$68,960
Pennsylvania	16,307	\$83,743
Rhode Island	1,127	\$79,651
South Carolina	10,024	\$77,113
South Dakota	1,189	\$60,131
Tennessee	10,564	\$71,970
Texas	46,025	\$78,129
Utah	2,063	\$61,717
Vermont	633	\$66,020
Virginia	13,323	\$73,994
Washington	7,461	\$71,967
West Virginia	2,633	\$77,206
Wisconsin	7,152	\$69,361
Wyoming	488	\$58,772
Puerto Rico	3,464	\$39,185
Foreign	52	\$41,270
Territories	954	\$47,236

KidneyWorks Expert Stakeholders

	Stakeholder	Organization
Patients	Ellen Griffith Cohen, JD	Kidney transplant recipient, retired Public Affairs Specialist at Centers for Medicare & Medicaid Services Central Office
	Paul T. Conway	Kidney transplant recipient, AAKP President, Kidney Health Initiative Board, Mid-Atlantic Renal Coalition (ESRD Network 5) Board
	Rosalind Joffe, MA	Patient with chronic illness, Owner of ciCoach – Chronic Illness Career Coach, Board of Directors of the Massachusetts Health Quality Partners
	Richard Knight, MBA	Kidney transplant recipient, AAKP VP & Chair of Public Policy, Mid-Atlantic Renal Coalition (ESRD Network 5) Board
Non-profits	Teri Browne, PhD, MSW, NSW-C	AAKP Board, Associate Professor at the University of South Carolina School of Social Work, Editor of <i>Journal of Nephrology Social Work</i>
	Diana Clynes, BA	AAKP Director of Programs & Services
	Richard Goldman, MD	AAKP Board, Chair of the Board of the Quality Initiative Network,

Stakeholder		Organization
		Past Chair of the Renal Physicians Association
	Gary Green	AAKP Executive Director
	Jenny Kitsen, BSW	AAKP Board, Treasurer of Donate Life CT, Past Executive Director of Network of New England (ESRD Network 1)
	Dori Schatell, MS	Executive Director of the Medical Education Institute (MEI)
	Amy E. Witten, BA	Consultant with MEI, Missouri Kidney Program Patient Education Program Kansas City Coordinator, Project Manager at Witten and Associates, LLC
	Beth Witten, MSW, ACSW, LCSW	Consultant with MEI, Founding Member of Witten and Associates, LLC, Past Chair of the National Kidney Foundation Council of Nephrology Social Workers
Professionals	Mary Beth Callahan, ACSW, LCSW	Transplant Social Worker at Dallas Transplant Institute, a subsidiary of Dallas Nephrology Associates, Past Chair of Council of Nephrology Social Workers
	Helen Currier, BSN, RN, CENP, CNN	Director of Renal and Pheresis Services at Texas Children's Hospital, Board of Directors of the National Renal Administrators Association, Former Member of the Board of Directors of the Society for the Arts and Healthcare
	Ruth Kaluski, MS, CRC, LMHC	Director of Career Connection Employment Resource Institute at the Mental Health Association of New Jersey
	Patricia Painter, PhD	Exercise Physiologist and Research Associate Professor, Physical Therapy and Athletic Training at the University of Utah
	Rebecca Schmidt, DO, FACP, FASN	Renal Physicians Association President, Professor of Medicine and Chief of Nephrology at West Virginia University School of Medicine, Former Member of AAKP Medical Advisory Board, Medical Review Board of Mid-Atlantic Renal Coalition (ESRD Network 5), Medical Advisory Board for NKF of the Alleghenies
Industry	Anne Bailey, BA, MS, MBA	Group Vice President at DaVita
	Maggie Gellens, MD	Medical Director at Baxter Healthcare
	Douglas S. Johnson, MD	Director and Vice Chair of the Board of Dialysis Clinic, Inc.
	Louise Kato, MSW, MBA	Patient Quality of Life Services Director at Northwest Kidney Centers
	Dugan Maddux, MD	Fresenius Vice President of Kidney Disease Initiatives
	Sally Reppucci	Renalogic Vice President of Operations and Technology
	Allison Teitelbaum, MS, MPH, CAE	American Health Quality Association Senior Director of Health Programming and Strategy
Government	Elena Balovlenkov, MS, RN	Health Insurance Specialist at Centers for Medicare & Medicaid Services
	Meredith DeDona, MPH	Senior Policy Advisor in the Office of Disability Employment Policy at the U.S. Department of Labor
	Andrew Narva, MD	Director of National Kidney Disease Education Program at the National Institutes of Health, Chief Clinical Consultant for Nephrology for the Indian Health Service
	Robert Walsh	Health Resources & Services Administration Senior Advisor

SECTION 1: BACKGROUND

Chapter 1: Helping People with Chronic Kidney Disease to Keep Their Jobs

“Illness is like any adversity: it must be viewed as a challenge you can meet. You need to have a clear vision...where you are, where you have strengths and the clarity to move forward...and workplace success can be transforming. It gives you the power and confidence to face challenges large and small.

Continuing to work while living with a chronic illness can allow a person to maintain key elements that promote well-being. Work provides routine and structure, income and benefit. It can also promote self-esteem and purpose and social interaction.”

Rosalind Joffe*

**All quotes in this document are from individuals who have a chronic disease or who specifically have chronic kidney disease.*

In the United States, more than 20 million adults are estimated to have Stage 1-5 **chronic kidney disease (CKD)**,¹ which can lead to **kidney failure (end-stage renal disease, ESRD)***. People whose kidneys fail require dialysis or a kidney transplant to survive. KidneyWorks focuses on Americans with *non-dialysis* chronic kidney disease (ND-CKD): those whose kidneys have not yet failed. *A Glossary of Terms can be found in **Appendix A**.

There are strategies to delay or prevent progression of CKD to ESRD.² **For working-age people with CKD, keeping a job that provides a health plan or income to purchase one helps ensure access to preventive care they desperately need to delay or avoid kidney failure—and remain active, productive, tax-paying citizens.** CKD symptoms can pose challenges for remaining employed—however, these symptoms can be treated.

An underappreciated burden of unemployment is that working always pays more than disability does,³ **which lets workers feel productive, pay bills, and contribute to society.**

Conversely, not working can have ill effects. People who want to work but are unemployed are prone to depression. In a 2013 Gallup poll, among 18,322 Americans who were unemployed, those who were out of work for 27 or more weeks had more than triple the rate of depression

¹ National Institutes of Diabetes and Digestive and Kidney Diseases. Kidney Disease. <https://www.niddk.nih.gov/about-niddk/research-areas/kidney-disease/pages/kidney-diseases.aspx> Accessed 9/21/2016

² Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney inter.*, Suppl. 2013; 3: 1-150

³ Social Security Administration. Monthly Statistical Snapshot, July 2016 https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/. Accessed September 4, 2016

treatment of full-time workers (18% vs. 5.6%).⁴ Compared to other chronic illnesses, such as diabetes and heart disease, kidney disease seems to cause more people to have depression.⁵

For the 53% of people with CKD who are working-age, keeping a job helps ensure access to preventive care they desperately need to delay or avoid kidney failure—and to remain active, productive, tax-paying citizens. Working creates routines and boosts self-esteem, income, feelings of purpose, and social interaction. CKD symptoms can pose challenges for keeping a job—but, most of these symptoms can be effectively treated. Children who have kidney disease need to remain in school so they can be productive when they become adults.

Many working-age people with CKD *do* work—but many lose their jobs. The only national data are from the Medicare CMS Form 2728 which collects employment status 6 months prior to and at the start of dialysis or a kidney transplant.⁶ **Between 2006 and 2014, 68,341 people with CKD lost their jobs in the 6 months before they developed ESRD.**⁷ Yet, it seems reasonable to expect that continued employment of people with CKD can:

- Improve people’s health, quality of life, and survival—and prevent disability
- Protect income and health benefits and offer as normal a lifestyle as possible
- Reduce costs to Medicare, Medicaid, and federal and state support programs
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For many Americans, employment gives life a sense of *purpose*. And, while all those with CKD expend time and money to treat their illness, not being able to work due to CKD has costs such as:

- Lower lifetime income and retirement earnings and savings
- Unplanned life decisions and deferrals of major decisions such as home purchases
- Fear, anxiety, and stress on family and loved ones
- Loss of relationships and friendships, and sense of identity

Societal costs of preventable dependency and disability for those with ND-CKD include:

- Lost federal and state tax revenue
- Reduced workforce productivity and GDP
- Greater healthcare expenditures for both patients and the taxpayers
- Increased federal spending for disability, Medicare, and Medicaid

⁴ Crabtree S. In the U.S., depression rates higher for long-term unemployed. <http://www.gallup.com/poll/171044/depression-rates-higher-among-long-term-unemployed.aspx>. Accessed November 18, 2016

⁵ Kimmel PL, Cukor D, Cohen SD, Peterson RA. Depression in end-stage renal disease patients: a critical review. *Adv Chronic Kidney Dis*. 2007 Oct;14(4):328-34

⁶ United States Renal Data System. 2016 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2015. Volume 2, ESRD, Table C.2

⁷ USRDS. 2016 ADR. Volume 2, ESRD, Table C.2 (calculation)

Employment Challenges Facing People with CKD

What factors contribute to job loss among CKD patients? Could the loss of jobs be due to a combination of symptoms, depression, hopelessness, fear, and a belief that a disability check will provide sufficient income, or could it be something else? More research is needed to determine barriers. However, if barriers can be identified, steps can be taken to overcome them. Overcoming them will require empowered, engaged and well-informed CKD patients and families and knowledgeable providers who are prepared to educate CKD patients about their prognosis and treatment options. Treatment options should be presented within the context of each patient's goals and expectations, and should include each option's risks (including potential loss of employment), benefits, and burdens. Another important action is to detect and treat those with CKD *before* they reach end-stage, called non-dialysis CKD, or ND-CKD. **Yet, to date, there has never been an initiative to help people with ND-CKD keep their jobs, their income, and the vital self-worth that is built through work and self-sufficiency.**

*The American Association of Kidney Patients (AAKP) and the Medical Education Institute (MEI), two non-profit kidney organizations, are spearheading **KidneyWorks™** a collaborative effort to **keep CKD patients employed, slow progression of kidney disease, and help working Americans avoid a life on disability.** In June 2016, a team of expert stakeholders from all sectors of the kidney community—patients, non-profits, professionals, members of industry and representatives from the Federal government—met in Washington, D.C. to address challenges facing employed people with CKD who may be at risk for kidney failure, and discuss strategies to help them keep their jobs and their dignity. This White Paper reports their conclusions.*

Why Does KidneyWorks Focus on People with Non-Dialysis CKD and Not Those on Dialysis?

U.S. Bureau of Labor Statistics reported on June 21, 2016 that in 2015, **72.2%** of Americans ages 16-64 in the general population were working—26.9% of them were working with a disability.⁸ **Yet, only 16% of those on dialysis ages 18-54 were working full- or part-time in 2014, the most recent year national data were reported.**⁹ Instead, most receive disability payments. Trying to get those on dialysis *back* to work is extremely difficult. In 2014, 87.9% had hemodialysis in a clinic¹⁰ three days per week during the workday. Also, many feel exhausted for hours after each treatment.¹¹ Therefore, MEI and AAKP, two independent, allied, passionately committed organizations trying to make a difference in the lives of people at all stages of CKD, are taking on the challenge of going “upstream,” prior to disability, to help employed ND-CKD patients *keep* their jobs and health plans. ***We believe that preventing unemployment in the first place is the best strategy.***

⁸ U.S. Department of Labor, Bureau of Labor Statistics. News Release: Persons with a Disability: Labor Force Characteristics — 2015. <http://www.bls.gov/news.release/pdf/disabl.pdf>. Accessed March 31, 2017.

⁹ USRDS. 2016 ADR. Volume 2, ESRD, Table J.10

¹⁰ USRDS. 2016 ADR. Volume 2, ESRD, Table D.11

¹¹ Rayner HC, Zepel L, Fuller DS, Morgenstern H, Karaboyas A, Culleton BF, Mapes DL, Lopes AA, Gillespie BW, Hasegawa T, Saran R, Tentori F, Hecking M, Pisoni RL, Robinson BM. Recovery time, quality of life, and mortality in hemodialysis patients: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis.* 2014 Jul;64(1):86-94

KidneyWorks Phase 1 Stakeholder Meeting

KidneyWorks was rolled out on Capitol Hill at a meeting of stakeholders at the Hall of States Building in Washington D.C. on June 29-30, 2016, with 29 national experts in patient engagement, kidney care, health and insurance data mining, labor force data mining, Federal reimbursement policy, physical exercise, renal social work, and vocational rehabilitation in attendance. The expert participants identified issues and barriers that interfere with the goal of continuing employment despite progressive ND-CKD, then formulated consensus strategies and recommendations to help patients maintain their employment, and their incomes and standards of living. Attendees at the KidneyWorks Stakeholders Meeting were listed on pages 12-13 of this White Paper.

KidneyWorks Sponsors

AAKP and MEI express their deep appreciation to the sponsors of the KidneyWorks™ Initiative's Stakeholder Conference:

- ***Baxter International Inc.***
- ***DaVita, Inc.***
- ***Dialysis Clinic, Inc.***
- ***Fresenius Kidney Care***
- ***National Renal Administrators Association***
- ***Northwest Kidney Centers***
- ***Renal Medicine Foundation***
- ***The former New York End-Stage Renal Disease Network***

Chapter 2: A Brief Overview of Disability in the General Population

“You can imagine the challenges I faced getting my health under control with two autoimmune illnesses, but in fact for me...returning to work was the biggest challenge. Everyone thought I should quit working...the books, family and friends, the people I talked with...everyone but my husband all said that work equals stress: ‘Stress is bad if you have a chronic illness. Stop working, that’s obvious.’ But it wasn’t obvious to me.”

Rosalind Joffe

To better understand disability and unemployment with non-dialysis CKD (ND-CKD), it is helpful to understand the general context of disability in the U.S. *Half* of American adults have at least one chronic disease;¹² thus, many—if not most—U.S. employers already have one or more employees who are negotiating a balance between work life and illness.

Prevalence of Disability in the United States

The United States Bureau of Labor Statistics (BLS) surveys households of those over age 15 and asks 6 questions to identify those who are disabled. People with CKD may be classified by the BLS as disabled for a reason *other* than kidney disease if they answer “yes” to:

- Is anyone deaf or does anyone have serious difficulty hearing?
- Is anyone blind or have serious difficulty seeing even when wearing glasses?
- Because of a physical, mental, or emotional condition, does anyone have serious difficulty concentrating, remembering, or making decisions?
- Does anyone have serious difficulty walking or climbing stairs?
- Does anyone have difficulty dressing or bathing?
- Because of a physical, mental, or emotional condition, does anyone have difficulty doing errands alone such as visiting a doctor’s office or shopping?¹³

According to the CDC’s National Health Interview Survey (2015), of those ages 18-64 who reported having been told they had “weak or failing kidneys,” 22.4% were working full or part-time, 72.7% were unemployed but worked previously, and only 4.9% never worked.

How Disability Payments Compare with Earned Income

Disability programs are a safety net, but recipients without other income may remain below federal poverty level for their household size, as shown in Table 1.¹⁴

¹² Centers for Disease Control and Prevention, <http://www.cdc.gov/chronicdisease/overview/>, accessed September, 2016

¹³ U.S. Department of Labor Bureau of Labor Statistics. Labor Force Statistics from the Current Population Survey. Frequently Asked Questions about Disability Data. http://www.bls.gov/cps/cpsdisability_faq.htm#Identified. Accessed September 4, 2016

¹⁴ US Department of Health & Human Services. Office of the Assistant Secretary for Planning and Evaluation. Poverty Guidelines. <https://aspe.hhs.gov/poverty-guidelines>. Accessed January 20, 2017

Table 1: Federal Poverty Level (Published annually in late January)

2016 Federal Poverty Level in the 48 Contiguous States*	
Persons in family/household	Poverty guideline
1	\$11,880
2	\$16,020
3	\$20,160
4	\$24,300
5	\$28,440
6	\$32,580
7	\$36,730
8	\$40,890

For families/households with more than 8 persons, add \$4,160 for each additional person.

*Poverty levels for Alaska and Hawaii are somewhat higher.

Social Security Disability does not fully replace work income. In July 2017, the average monthly Social Security Disability Insurance (SSDI) individual benefit was \$1,171 (annualized to \$14,052).¹⁵ **The maximum family benefit is 150–180% of a disabled individual’s benefit—and the more a recipient earns, the less is replaced.** Table 2 below shows SSDI payment vs. earned income in 2014:¹⁶

Table 2: Work Income versus SSDI

Earnings Prior to Disability	Social Security Replaces	SSDI Annual Amount
\$20,000	60%	\$12,000
\$40,000	46%	\$18,400
\$60,000	41%	\$24,600
\$113,700*	28%	\$31,836

*The maximum income subject to Social Security taxation in 2013

Supplemental Security Income (SSI) provides even less income than SSDI. The maximum federal benefit for low-income recipients in 2016 is \$733 per month (annualized to \$8,796); a couple who both qualified for SSI that year would receive \$1,100 per month, or \$13,200/ year.

Employment permits a dramatically higher standard of living than SSDI and SSI.

¹⁵ Social Security. Fact Sheet: 2017 Social Security Changes. <https://www.ssa.gov/news/press/factsheets/colafacts2017.pdf>. Accessed January 20, 2017

¹⁶ National Association of Social Insurance. What is Social Security Disability Insurance? <https://www.nasi.org/learn/socialsecurity/disability-insurance>. Accessed September 13, 2016

Chapter 3: Non-dialysis CKD and Employment in the United States

“They told me that I’d feel tired, but I was 50ish and able to put in a 50-hour week...If you tell patients what to expect from CKD, they can be better prepared to deal with it. I could have made accommodations. Being aware of what to expect is half the battle.”

Richard Knight

Healthy kidneys regulate chemical and acid-base balance in our bodies. In addition, kidneys, make hormones that maintain bone health, trigger red blood cell production, control blood pressure, and remove wastes and excess water. Thus, when kidneys begin to fail, most body systems are affected.

The continuum of CKD from slight damage to severe kidney failure is divided into 5 stages based on **estimated glomerular filtration rate** or eGFR—roughly the percent of existing kidney function. The rate of CKD progression is assessed by repeating eGFR measurements over time.

The amount of albumin (a protein in the blood) excreted in urine is also tested, using an albumin-to-creatinine ratio (UACR). In any given individual, CKD may progress over time to kidney failure—or it may not. Many who have stage 3 CKD will never progress to kidney failure during their lifetimes and will die from another cause, typically heart disease.¹⁷ The risk that CKD *will* progress is higher when the eGFR is below 30-44 ml/min/1.73 m² and the urine ACR is above 30 mg/g in two lab tests 3-months apart.¹⁸

Figure 1 illustrates the CKD stages and progression risk.¹⁹

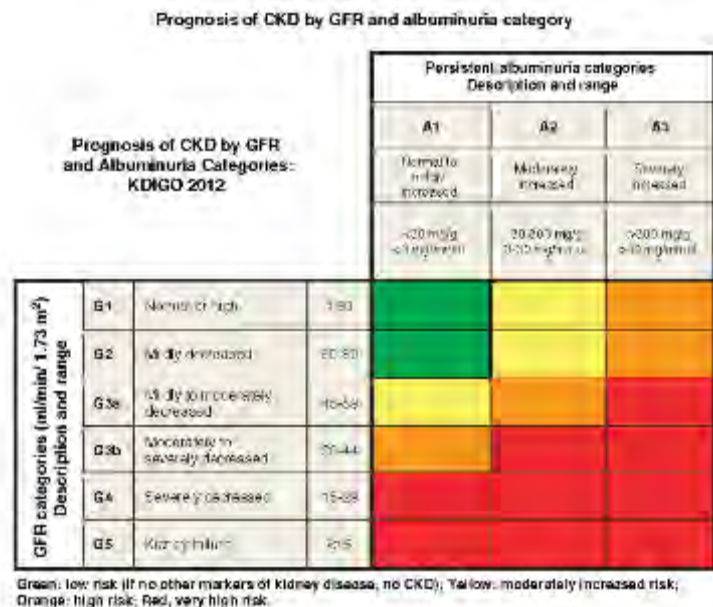


Figure 1: Current Chronic Kidney Disease (CKD) Nomenclature Used by KDIGO

Graph reprinted with permission from the National Kidney Foundation, Inc.

¹⁷ Coresh J, Turin TC, Matsushita K, Sang Y, Ballew SH, Appel LJ, Arima H, Chadban SJ, Cirillo M, Djurdjev O, Green JA, Heine GH, Inker LA, Irie F, Ishani A, Ix JH, Kovesdy C, Marks A, Ohkubo T, Shalev V, Shankar A, Wen CP, de Jong PE, Iseki K, Stengel B, Gansevoort RT, Levey AS for the CKD Prognosis Consortium. Decline in estimated glomerular filtration rate and subsequent risk of end-stage renal disease and mortality. *J Am Med Assoc.* 2014 June 25;311(24):2518-31

¹⁸ Inker LA, Astor BC, Fox CH, Isakova T, Lash JP, Peralta CA, Kurella Tamura M, Feldman HI. KDOQI US commentary on the 2012 KDIGO clinical practice guideline for the evaluation and management of CKD. *Am J Kidney Dis.* 2014 May;63(5):713-35

¹⁹ Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Int., Suppl.* 2013; 3: 1-150

At some point during stage 5 CKD, *end-stage renal disease* (ESRD), permanent kidney failure occurs. At that time, the individual can choose conservative management which will lead to death or he/she may limit fluids, make strict dietary changes, take several medicines, and choose to do dialysis or have a kidney transplant to survive. **The focus of KidneyWorks is CKD prior to the need for dialysis or transplant: non-dialysis CKD, or ND-CKD.**

KidneyWorks Stakeholder Consensus on Barriers to ND-CKD Employment

Subject matter experts in the Stakeholder group came to consensus that *many* factors can interfere with employment of people with CKD, in particular:

- Presence (with or without recognition of their relationship to CKD) of work-limiting symptoms such as fatigue, weakness, and brain fog, and fears that these symptoms will hamper performance or cause missed work days
- Feeling overwhelmed by life changes and the unpredictability of chronic illness
- Lack of education about how to slow kidney disease, work rights, and how to keep a job
- Mixed messages about working from family and friends
- Uncertainty about when and how to communicate with an employer
- Real or perceived employment discrimination
- People with CKD may be concerned about coworkers perceiving preferential treatment
- Lack of job flexibility to schedule medical appointments
- Healthcare provider beliefs that patients can't or don't work
- The availability of disability as a seemingly "attractive" option
- For children, school environments that do not support attendance with a chronic illness

Causes and Demographics of CKD

CKD Causes

The two leading causes of kidney failure in the United States are type 2 diabetes and high blood pressure,²⁰ both of which are increasingly common among Americans. Figure 2 illustrates the percentage of individuals with each cause of kidney failure.²¹ Those with Type 1 diabetes who develop ESRD tend to do so at a younger age than those with type 2 diabetes. Heart disease and a family history of kidney disease are risk factors as well.²²

²⁰ USRDS 2015 ADR, volume 2, ESRD, Table A7

²¹ USRDS. 2016 ADR. Volume 2, ESRD, Table A.7

²² <https://www.niddk.nih.gov/health-information/health-communication-programs/nkdep/identify-manage/identify-evaluate/Pages/evaluate-patients.aspx>, Accessed September 2, 2016

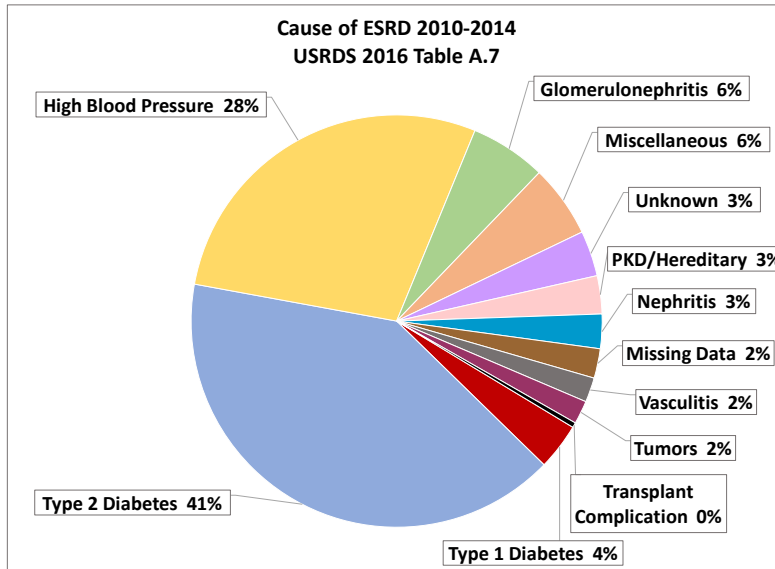


Figure 2: Causes of ESRD

Race and Ethnicity of Americans with ND-CKD

Non-white and Hispanic/Latino Americans are more likely to report that a doctor has diagnosed them with kidney problems. The impact on minorities, who are at higher risk for CKD and kidney failure than whites, is even more alarming. Figure 3 below shows the breakdown of race in the ND-CKD population.²⁴

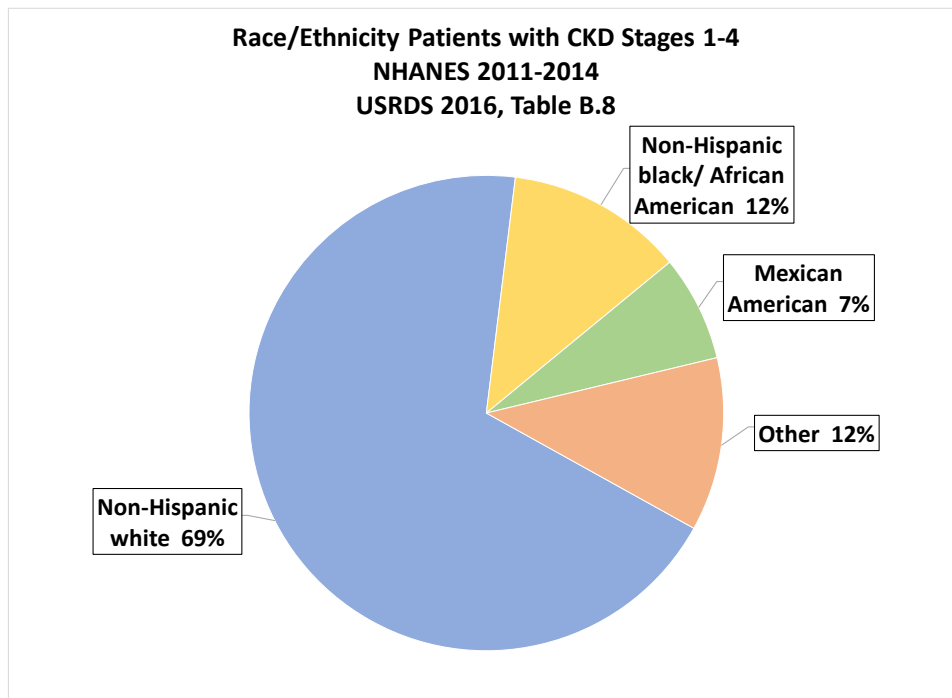


Figure 3: Race/Ethnicity CKD Stage 1-4

Working-Age and ND-CKD Prevalence in Americans

Almost 2.2 million working-age Americans between ages 18 and 64 have some degree of ND-CKD. The National Health and Nutrition Examination Survey (NHANES) of a large representative survey of American adults estimates that stage 1-4 CKD is present among:²³

- **20.8%** of those ages **20-44**
- **13.8%** of those ages **45-54**
- **17.7%** of those ages **55-64**

Figure 4 shows the percentage of those with ND-CKD who are age 20 and older.²⁴ More than half are under age 65.

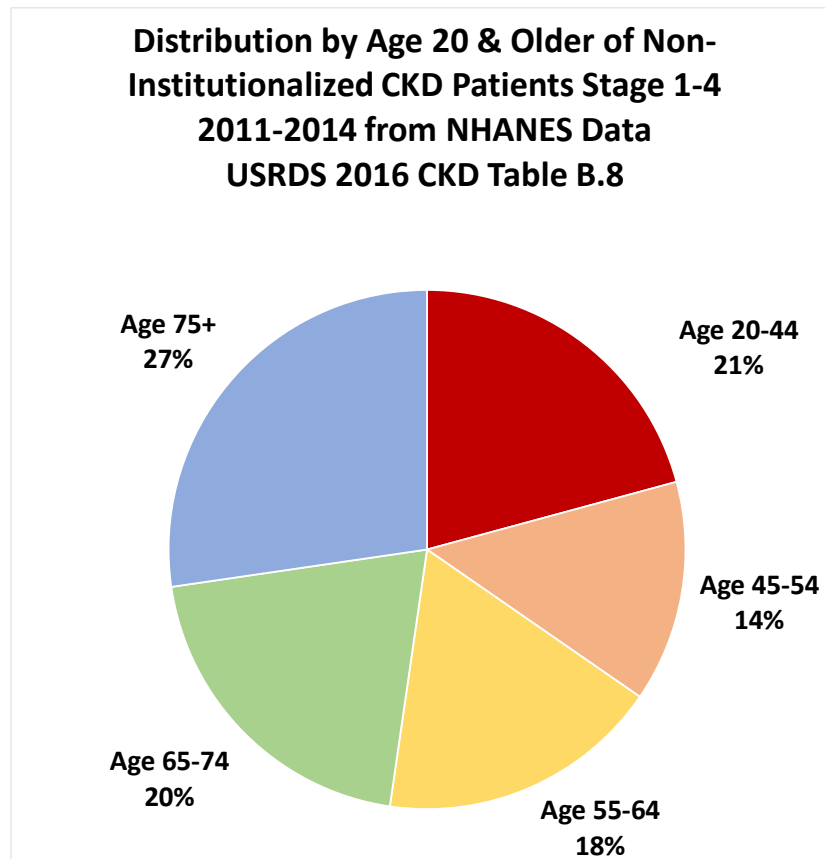


Figure 4: ND-CKD Patients by Age

Estimated Prevalence of ND-CKD by State

The CDC's Behavioral Risk Factor Surveillance System (BRFSS) collects data on individuals in each state. Figure 5 shows an estimate of how many American adults had been told by a healthcare professional that they have kidney disease (darker green = higher rate).²⁵

²³ USRDS. 2016 ADR. Volume 1, CKD, Table B.8

²⁴ USRDS. 2016 ADR. Volume 1, CKD, Table B.8

²⁵ USRDS. 2016 ADR. Volume 1, CKD, Chapter 1. PowerPoint Slide #28. <https://www.usrds.org/2016/view/Default.aspx>.

Accessed January 25, 2017

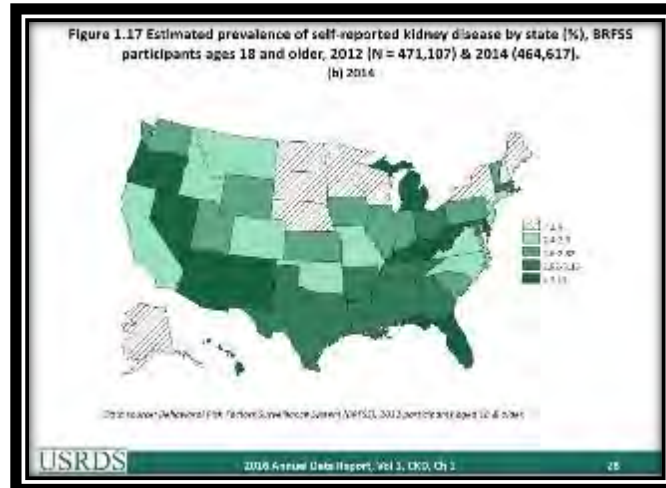


Figure 5: Estimated Prevalence of ND-CKD by State

Adjusted Incidence of ESRD by Health Service Area (HSA) in 2014

A USRDS special study of the incidence rate of ESRD (new patients) adjusted by age, race, and sex based on the U.S. population in 2011 found that there was a higher rate of new patients with ESRD in certain HSAs (darker green = higher rate).²⁶ See Figure 6.

Figure 1.3 Map of the adjusted* incidence rate (per million/year) of ESRD, by Health Service Area, in the U.S. population, 2014

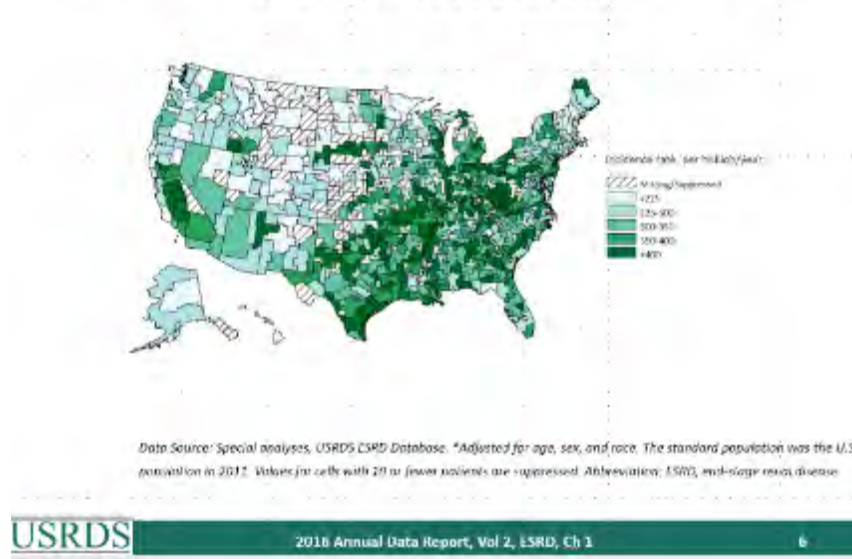


Figure 6: Adjusted Incidence Rate by Health Service Area

Projected Increase in ND-CKD

In 2010, 13.2% of the U.S. population aged 30 or older had CKD, a figure that is projected to rise to 14.4% by 2020—and to 16.7% by 2030.

²⁶ USRDS. 2016 ADR. Volume 2, ESRD, Chapter 1, PowerPoint Slide #6 <https://www.usrds.org/2016/view/Default.aspx>. Accessed January 25, 2017

Socioeconomic Status, ND-CKD, and Employment Levels in the United States

As in the general population, lower socioeconomic status (SES)— less education and income— raises the risk that ND-CKD patients will become disabled, regardless of race/ethnicity, comorbid conditions, and access to healthcare.²⁷ Those with low SES may have greater difficulty self-managing CKD. They may not be able to afford to treat conditions like diabetes and hypertension that can damage their kidneys.²⁸ Based on data collected by the National Health Interview Survey of American adults, we know that:

- **CKD prevalence is rising:** Fewer than 2% of those over 18 were told by a clinician in the last 12 months that they have “*weak or failing kidneys (excluding kidney stones, bladder infections, or incontinence)*”—but this figure rose from fewer than 4 million in 2012 to nearly 4.85 million in 2015.
- **People with CKD are less likely to work:** Of those who were told they had CKD, 76% were not employed, but had worked before. About half were ages 18-64; 2.5 million were 65+.²⁹

For resources and employment-related data for people with kidney disease, see **Appendix F**.

Potentially Work-limiting CKD Symptoms

Because so many bodily functions are supported by the kidneys, a variety of potentially work-limiting symptoms can occur as the kidneys failure, as early as stage 3a or when the GFR declines below 60 ml/min/1.73m².³⁰ These may include:

- Fatigue
- Feeling dizzy, faint, or lightheaded
- Swelling in the hands, feet, or face
- Shortness of breath
- Itching
- Feeling cold all the time
- Trouble concentrating, “brain fog”
- Loss of appetite, protein aversion, a metallic taste in the mouth
- Sleep problems including restless legs syndrome and sleep apnea
- Nausea and vomiting
- Depression
- Weakness
- Exercise intolerance

²⁷ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center on Health Statistics. Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2014 http://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2014_SHS_Table_A-4.pdf. Accessed September 4, 2016

²⁸ Plantinga LC, Johansen KL, Schillinger D, Powe NR. Lower socioeconomic status and disability among US adults with chronic kidney disease, 1999-2008. *Prev Chronic Dis.* 2012;9:E12

²⁹ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center on Health Statistics. Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2015, Table A-4b https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2015_SHS_Table_A-4.pdf

³⁰ National Kidney Foundation, Kidney Disease Outcomes Quality Initiative, Guideline 12: Association of GFR with Indices of Functioning and Well-being, http://www2.kidney.org/professionals/KDOQI/guidelines_ckd/p6_comp_g12.htm, Accessed September 2, 2016

The stress of not knowing the short and long-term effects of this serious chronic illness can weigh heavily on patients. And, those who do not remain physically active may become frail. Changes in cognitive functioning (“brain fog”) can adversely affect ability to focus.³¹ **CKD patients need knowledge, strategies, tools, and support to manage these symptoms and remain productive in the workplace.** They may be an employer’s most motivated and loyal workers, due to their desire to maintain employment and benefits.

Kidney Transplant Recipients as ND-CKD Patients

A successful transplant replaces some of the lost function of the failed kidneys with one healthy kidney from a living or deceased donor. With a functioning transplant, there is no need for dialysis, and the new kidney function closely approximates normal kidney function. Quality of life and survival tend to be much better with a transplant than on the standard in-center hemodialysis most Americans with kidney failure receive three times a week.³² However, a transplant also requires powerful and costly immunosuppressant medications, which can create serious new health issues, including a 25% incidence of new onset diabetes³³ and a 13.9% incidence of cancers in the first 3 years.³⁴ And, a transplant can fail at any time. A kidney transplant is a treatment for kidney failure—not, as is often portrayed in the media, a cure.

Working-age patients whose health insurance is through Medicare lose Medicare eligibility after 3 years unless they *also* have a non-kidney-related qualifying disability. Someone who has no job-provided insurance, cannot afford an individual plan and does not qualify for Medicaid, can find immunosuppressant medications to be cost-prohibitive. Even with a Marketplace plan, someone who does not receive tax credits to help pay for health insurance premium and/or income-based subsidies may have trouble paying the out-of-pocket costs for their medical care, including drugs. Thus, returning to the workforce and obtaining employer-provided health insurance or earning enough to afford both a Marketplace plan *and* its out-of-pocket costs—\$7,150 in 2017—can mean the difference between keeping and losing a kidney transplant.

Finally, successful transplants do not *fully* restore kidney function. A study of transplant recipients found that 45% of 507 recipients in two centers had stage 3 CKD, and 19% had stage 4 or 5.³⁵ **Transplant recipients are ND-CKD patients who need support to maintain employment and afford their costly medications, which help them to keep their kidney and avoid work-limiting dialysis.**

³¹ Plantinga LC, Johansen K, Crews DC, Shahinian VB, Robinson BM, Saran R, Burrows NR, Williams DE, Powe NR; CDC CKD Surveillance Team. Association of CKD with disability in the United States. *Am J Kidney Dis*. 2011 Feb;57(2):212-27

³² Painter P, Krasnoff JB, Kuskowski M, Frassetto L, Johansen K. Effects of modality change on health-related quality of life. *Hemodial Int*. 2012 Jul;16(3):377-86

³³ Suarez O, Pardo M, Gonzalez S, Escobar-Serna DP, Castaneda DA, Rodriguez D, Osorio JC, Lozano E. Diabetes mellitus and renal transplantation in adults: is there enough evidence for diagnosis, treatment, and prevention of new-onset diabetes after renal transplantation? *Transplant Proc*. 2014 Nov;46(9):3015-20

³⁴ Dharnidharka VR, Naik AS, Axelrod D, Schnitzler MA, Xiao H, Brennan DC, Segev DL, Randall H, Chen J, Kasiske B, Lentine KL. Clinical and economic consequences of early cancer after kidney transplantation in contemporary practice. *Transplantation*. 2016 Aug 3

³⁵ Sangalli V, Dukes J, Doppalapudi SB, Costa G, Neri L. Work ability and labor supply after kidney transplantation. *Am J Nephrol*. 2014;40(4):353-61

Kidney Transplantation and Employment in the U.S.

Working-age patients who have jobs *before* a kidney transplant are more likely to keep working afterward. One study looked retrospectively at 30 patients, then followed 150 who received care to prevent transplant complications as well as employment counseling and social support.³⁶ The researchers found that 85.6% of those who were employed before their transplant were still working 6 months afterward, and by 12 months, 87.8% were back to work. In the same study, among recipients who were *unemployed* before transplant, just 42% were working at 6 months—but 86% were working at 12 months later.

Transplant recipients work in a variety of industries, from health and social work to trade, construction, community, social, and personal services.³⁷ Most held positions that required both mental and physical energy (54.4%). Their broad range of jobs included:

- Management (9%)
- Supervisory/middle management (22.6%)
- Administrative/clerical (18.4%)
- Skilled laborers (17.9%)
- Unskilled laborers (9.5%)

Insurance is a factor in continued employment of kidney transplant recipients. A retrospective analysis of employment rates after kidney transplant from 2004-2011 in the United Network for Organ Sharing (UNOS) database showed that those who had private health coverage were far more likely to still be employed than those with Medicare or Medicaid, as shown in Table 3.³⁸

Table 3: Health coverage post-transplant

Health Coverage	% Employed 1-Year Post-Transplant	% Employed 3-Years Post-Transplant	% Employed 5-Years Post-Transplant
Private Insurance	47.5%	44%	43%
Medicare	16%	13.5%	12%
Medicaid	<1%	<1%	<1%

Transplant recipients who have health insurance through a job may be more motivated to keep working—or may have better jobs. These individuals would be targets for KidneyWorks. Those under age 65 who still had Medicare more than 3-years post-transplant are likely to be disabled by a *non-kidney-related* condition and may not be appropriate for KidneyWorks.

³⁶ Chang CF, Winsett RP, Gaber AO, Hathaway DK. Cost-effectiveness of post-transplantation quality of life intervention among kidney recipients. *Clin Transplant*. 2004 Aug;18(4):407-14

³⁷ Sangalli V et al., 2014, IBID

³⁸ Tzvetanov I, D'Amico G, Walczak D, Jeon H, Garcia-Roca R, Oberholzer J, Benedetti E. High rate of unemployment after kidney transplantation: analysis of the United network for organ sharing database. *Transplant Proc*. 2014 Jun;46(5):1290-4

Older age does not appear to be a major factor in return to work post-transplant, especially after 3 years.³⁹ Table 4 shows, in fact, more patients were working after 3 years post-transplant, especially those age 51-65. One hypothesis for greater employment after 3 years post-transplant is that non-disabled transplant recipients under age 65 may be more motivated to work because Medicare coverage ends then and other insurance is necessary to cover expensive immunosuppressants.

Table 4: Employment by Age and Time from Transplant

Age	Working <12 Mo Post-Transplant	Working >3 Years Post-Transplant
20-35	64.3%	71.4%
36-50	48.8%	61.9%
51-65	41.2%	68.3%

Medicare, Employment, and Kidney Disease

Most Americans with chronic illnesses cannot receive Medicare until they are over age 65 or have received SSDI for 24 months. Yet, ESRD has been an exception for decades: citizens with enough work credits qualify for Medicare when they need dialysis or a kidney transplant. Why is kidney failure different? A shortage of life-saving dialysis equipment and supplies in the 1960s led to unprecedented healthcare rationing.⁴⁰ In response to vivid stories and public outcry, Congress passed PL 92-603, the Medicare ESRD Program, and President Richard Nixon signed it into law on October 30, 1972. Senator Vance Hartke spoke in favor of the bill, on the basis that: **“60% of those on dialysis can return to work but require retraining, and most of the remaining 40% require no retraining whatsoever. These are people who can be active and productive, but only if they have the life-saving treatment they need so badly.”**

Due to an aging and increasingly chronically ill population, the initial promise of the Medicare ESRD Program has *not* been realized. **To help people with ND-CKD keep their jobs, we must identify them early and act before their kidneys fail, even though they may not yet be eligible for Medicare.** For a more detailed description of the fascinating history of dialysis and Medicare, see Appendix B.

Disability vs. Work

Americans with ND-CKD *alone* can qualify for disability benefits from Social Security *only* if they have the signs, symptoms, or laboratory values described in detail in **Appendix C: Disability Evaluation Under Social Security**. Social Security Work Incentives can be found in **Appendix D**. Federal employment, healthcare, and disability laws can be found in **Appendix E**.

Some patients are eligible for public or private disability payments due to another serious health condition. In 2014, almost 300,000 Americans ages 20-64 with ND-CKD were estimated

³⁹ Sangalli V et al, 2014, IBID

⁴⁰ Blagg, CR. The early history of dialysis for chronic renal failure in the United States: A view from Seattle. *Am J Kidney Dis*. 2007 Mar;49(3):482-98

to already *have* Medicare based on a 5% sample. This suggests that they were entitled to Medicare due to disability and prior work status, since they were under age 65.⁴¹

Medicare Costs for People with Kidney Disease

While total costs for all ND-CKD patients are difficult to obtain, the **Medicare-only costs in 2014 for ND-CKD exceeded \$58 billion per year**—and these include *only* those who are over age 65 or already disabled for at least 24 months and entitled to Medicare due to disability.⁴²

A table on page 9-10 of the White Paper summary shows the data by state of the number of people with *kidney failure* and the average Medicare costs per patient by state in 2014.⁴³ **Keeping patients working would save federal, state, and local governments money in healthcare costs and provide economic benefits.**

⁴¹ USRDS. 2016 ADR. Volume 1, CKD, Table B.2

⁴² USRDS. 2016 ADR. Volume 1, CKD, Chapter 6

⁴³ USRDS. 2016 ADR, Volume 2, ESRD, Reference Tables, Table K.b.1 to 54 (Supp)

Chapter 4: Barriers to Maintaining Employment for People with Non-dialysis CKD

“As your kidneys are beginning to go, you also lose your resilience. The problem with disability is two things—to go for disability you have to prove what you can’t do when your health depends on you trying to prove to yourself and to others what you can do. You’re going in one direction to show you’re disabled and in another direction to show that it’s not that I’m disabled, it’s that the workload is too heavy. Or, I need accommodation.”

Ellen Griffith Cohen

For people with any chronic disease, including CKD, certain factors can make work more challenging—but many barriers to continued employment could be reduced.

Chronic Disease Barriers to Work

Barriers to CKD employment identified by the KidneyWorks stakeholder group:

- Patients may believe that disability is an attractive option.
- Healthcare providers may believe that patients cannot or do not want to work.
- Patients may not know their rights and when/how to talk with an employer about CKD.
- Patients may fear discrimination and have concerns about coworkers perceiving preferential treatment.
- Lack of education among some patients and medical professionals not in the kidney community about how to slow kidney disease.
- Children’s schools may not fully support their attendance with a chronic illness.
- Patients may receive mixed messages from family and friends about continuing to work.
- Patients may feel overwhelmed by life changes and the unpredictability of chronic illness.
- Patients may have work-limiting symptoms such as fatigue, weakness, and cognitive dysfunction (“brain fog”).

Several studies suggest factors that make employment with chronic disease more difficult:⁴⁴

- **Time constraints.** The need for multiple doctor visits—and the added time when clinicians are behind schedule—can stress workers with fixed schedules, and coworkers can resent time off that increases the workload on them.
- **Workplace discrimination.** Patients fear that they will not be hired initially if they reveal their condition(s) up front, or that they will be let go if it is discovered.
- **Symptoms.** Fatigue and unpredictable symptoms such as nausea or pain can make it hard to focus and be productive. Patients can be stressed if they fall behind because they don’t feel well.

⁴⁴ McQuoid J, Welsh J, Strazdins L, Griffin AL, Banwell C. Integrating paid work and chronic illness in daily life: A space-time approach to understanding the challenges. *Health Place*. 2015 Jul;34:83-91

One study shows these additional factors in play, some of which exist for all ND-CKD patients:⁴⁵

- **Financial security.** Patients who were closer to retirement age (ages 55-64) and already financially secure without working were less likely to continue to work post-transplant.
- **Difficulty of work.** Those whose work was especially arduous tended not to return to it. Having to work in weather extremes or under conditions that could expose them to infection risks was viewed as not worth risking the new kidney.
- **Cost of immunosuppressant medications.** The higher cost of insuring patients who have had a kidney transplant was viewed as a disincentive to hiring by potential employees.

Anemia as a Factor in CKD Patient Employment

Healthy kidneys produce a hormone (*erythropoietin*, or EPO) that tells the bone marrow to make red blood cells. As kidneys fail, one early complication is *anemia*: a red blood cell shortage that starves the tissues of oxygen and contributes to some of the work-limiting symptoms of CKD, including fatigue, lack of energy, concentration and memory problems, shortness of breath, dizziness, headache, and chest pain. The effects of anemia may be felt more acutely when the individual has a physically active job.

Anemia symptoms can begin early in CKD: 30% of patients with diagnosed anemia reported fatigue and low energy at Stage 3 CKD, and 50% by Stage 4.⁴⁶ As CKD progresses, severe symptoms of anemia might also affect patients' self-perceptions of their ability to work. Data from the USRDS for 2012-2014 show that the average hemoglobin (a test of anemia) for ND-CKD patients was 9.7 g/dL.⁴⁷ In healthy adult men, hemoglobin ranges from 14-18 g/dL and in healthy adult women, the range is 12-16 g/dL.⁴⁸

EPO levels can be boosted with erythropoietin stimulating agents (ESAs).⁴⁹ However, the United States Food and Drug Administration (FDA) issued a drug safety communication on June 24, 2011 regarding the safety of ESAs, including a Black Box Warning.⁵⁰ In 2014, only 19.7% of CKD patients had been treated with an ESA prior to ESRD.⁵¹ **Under-treatment of anemia may be one factor contributing to job loss in the last 6 months prior to kidney failure.**⁵²

⁴⁵ Nour N, Heck CS, Ross H. Factors related to participation in paid work after organ transplantation: perceptions of kidney transplant recipients. *J Occup Rehabil.* 2015 Mar;25(1):38-51

⁴⁶ Eriksson D, Goldsmith D, Teitsson S, Jackson J, van Nooten F. Cross-sectional survey in CKD patients across Europe describing the association between quality of life and anaemia. *BMC Nephrol.* 2016 Jul 26;17(1):97

⁴⁷ USRDS. 2016 ADR. Volume 2, ESRD, Table C.1

⁴⁸ Billett HH. Chapter 51: Hemoglobin and hematocrit. In *Clinical Methods: The History, Physical, and Laboratory Examinations*. 3rd edition. Walker HK, Hall WD, Hurst JW (Eds). Boston: Butterworths; 1990. <https://www.ncbi.nlm.nih.gov/books/NBK259/>. Accessed November 17, 2016

⁴⁹ Eschbach JW, Abdulhadi MH, Browne JK, Delano BG, Downing MR, Egrie JC, Evans JW, Friedman EA, Graber SE, Haley NR, et al. Recombinant human erythropoietin in anemic patients with end-stage renal disease. Results of a phase III multicenter clinical trial. *Ann Intern Med.* 1989 Dec 15;111(12):992-1000

⁵⁰ FDA Drug Safety Communication: Modified dosing recommendations to improve the safe use of Erythropoiesis-Stimulating Agents (ESAs) in chronic kidney disease. <http://www.fda.gov/Drugs/DrugSafety/ucm259639.htm>. Accessed September 4, 2016

⁵¹ USRDS. 2016 ADR. Volume 2, ESRD, Table C.10

⁵² USRDS. 2016 ADR. Volume 2, ESRD, Table C.2

SECTION 2: RECOMMENDATIONS

As noted above, the KidneyWorks stakeholders met in Washington, DC in June 2016. The professionally facilitated meeting elicited, among other things, the barriers to maintaining employment despite progressive CKD and recommendations for mitigating those barriers. The stakeholders reviewed relevant published literature on the subject as well as novel approaches recommended by the panel of KidneyWorks experts, including a research agenda.

In response to these barriers, KidneyWorks expert stakeholders made five core recommendations, as well as specific recommendations to several key audiences. Each of the recommendations below is discussed in greater detail in Chapters 5-9.

- 1. Raise awareness of CKD among the general public and those most at risk.** Use creative approaches to target employers, organizations, clinicians, patients and families with key messages.
- 2. Identify CKD early and provide optimal medical and psychosocial management.** Screen those at higher risk and use a team approach to empower patients and families to self-manage, share decision-making, and make lifestyle changes such as exercise that can help slow disease progression.
- 3. As soon as CKD is diagnosed, provide patients and family members with employment-supportive education.** To continue working, patients must learn to self-manage CKD, understand their rights on the job, and obtain job support. Education can help patients plan a treatment for kidney failure, should that occur, that allows them to work, such as transplant or home dialysis. Identify opportunities for education from early CKD to dialysis and transplant, with the assistance of agencies such as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the Health Resources and Services Administration (HRSA), and the National Kidney Disease Education Program (NKDEP) clearinghouse. Tailor information to their needs and offer it in a variety of formats—early and often.
- 4. Take active steps to slow CKD progression.** Help patients and implement effective interventions, including blood pressure and blood sugar control, exercise, weight loss, limiting dietary protein, and smoking cessation. Patients must also learn symptoms to watch for and report.
- 5. Support kidney transplant recipients in the workforce.** After a transplant, encouraging continued work, identifying meaningful work that creates a sense of purpose, encouraging employer flexibility, and offering vocational support are proven interventions to help people stay in the workforce.

Chapter 5: Recommendation—Raise Awareness of CKD among the General Public and Those Most at Risk

“How we talk about all these issues is so crucial. I totally advocate informing people and understanding that [how a patient feels day-to-day with] CKD is a spectrum that waxes and wanes.”
Rosalind Joffe

It is impossible to win a battle one does not even know exists. Most Americans have never heard of CKD—including far too many who *have the disease and don't know it*. Only those with stage 4 were well above the goals proposed for patient awareness by Healthy People 2020—yet, still, fewer than 50% of even those in stage 4 knew they had non-dialysis (ND-CKD) in a recent study of that initiative.

Communication about CKD: Factors Identified by KidneyWorks Participants

The KidneyWorks Stakeholder group agreed that communicating vital messages about CKD employment will require extensive collaboration and creativity in approaching employers, organizations, clinicians, patients and families with key messages. In particular, the group suggested that:

- The kidney community needs to effectively collaborate with other chronic disease organization and organizations knowledgeable about employment.
- CKD awareness must be enhanced, using as many communication venues as possible, such as churches, family picnics, talk radio and social media, particularly as those venues foster CKD-related support groups. Incorporating employment-related messages into National Kidney Month and World Kidney Day (both held in March each year) via outreach to the primary care physicians, family practitioners, specialists treating conditions that contribute to CKD, and American Society of Nephrology could help inform the general public and those who know they have ND-CKD.
- CKD awareness should be offered using as many different vehicles as possible including web based information, print or audio-video information in provider offices, or as part of CKD and treatment options education.
- To enhance patient awareness, those with CKD need to be taught about CKD, the disease process, related conditions, and signs and symptoms, taking into consideration the patient's health literacy. People with CKD can then be empowered to explain their condition to family, friends, employers and providers outside nephrology.
- To enhance public awareness of CKD, primary care practitioners should educate those with risk factors for developing CKD about how to screen for CKD and how important it is to be screened. Risk factors include diabetes, hypertension, heart disease, or a family history of kidney disease. African Americans, Hispanics, and Native Americans are at greater risk.⁵³

⁵³ National Kidney Disease Education Program. At Risk for Kidney Disease? <https://www.niddk.nih.gov/health-information/health-communication-programs/nkdep/learn/causes-kidney-disease/at-risk/Pages/are-you-at-risk.aspx>. Accessed September 5, 2016

Chapter 6: Recommendation—Identify CKD Early and Provide Optimal Medical and Psychosocial Management

“I knew I had to keep private health insurance. I knew I had to keep working. And this whole thing about a glide path until you crash was always in the back of my mind: keep your insurance up, that kind of thing.”

Paul Conway

Medical Management of CKD: Factors Identified by KidneyWorks Participants

A consensus was reached among KidneyWorks participants regarding CKD medical management.

- People with CKD should be engaged in managing CKD and should be empowered to share in decision-making concerning their care. This management may include changes in lifestyle if needed, eating a healthy diet, and regular exercise. A team approach should include early referral to social workers, dietitians and physical therapists when appropriate.
- Family members, especially those at risk for CKD, should be included in patient education to help them protect their health.
- The team should express confidence in patients’ ability to self-manage their health and treatment regimen.
- Providers should screen for CKD in high risk populations and refer those with ND-CKD to specialists who can manage and control disease progression.
- Patients should be informed that disability pays below the poverty level for many.
- Patients should be informed about the importance of exercise for improved energy and sense of well-being. This may include the use of activity trackers and/or software to encourage activity among those who choose these tools.

Today it’s easier than ever to identify people at risk earlier in the disease process through:

- Electronic health records, disease management companies, and self-insured companies
- Patient organization members, such as those belonging to the American Association of Kidney Patients who have early CKD and want to maintain their health and lifestyle
- Visitors to CKD websites

Identifying people at risk for CKD earlier could:

- Save healthcare dollars
- Slow CKD progression
- Decrease complications
- Prevent kidney failure

The Nephrologist's Collaborative Role in Optimal CKD Care

Nephrologists are trained to manage CKD and ESRD care. **Yet, the USRDS reports that 27.9% of patients had not seen a nephrologist even once before their kidneys failed.**⁵⁴ Figure 7 shows areas where earlier referrals to a nephrologist could be improved.⁵⁵

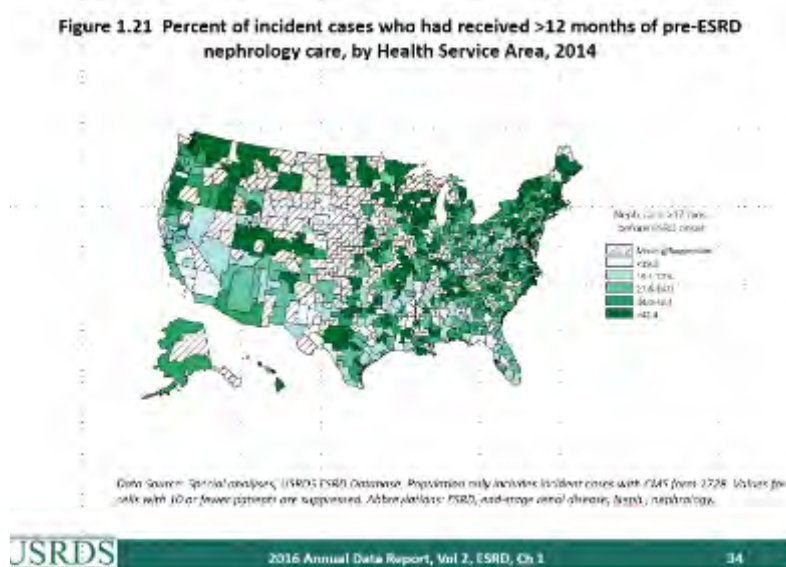


Figure 7: New ESRD Patients Treated by a Nephrologist for >12 Months Prior to ESRD by Health Service Area

Nephrologists can support patient employment by:

- Teaching patients how to slow CKD progression, promoting safe exercise, and asking patients about their values and goals, including employment, and helping them choose a treatment if their kidneys fail that will allow them to live a full life.
- Referring patients to dietitians, social workers, physical therapists, educators, and others who can support self-management and continued employment. Currently, most people do *not* receive the stage 4 CKD education Medicare has covered since 2010 under the Medicare Improvement for Patients and Providers Act (MIPPA) benefit. **In fact, in 2011, fewer than 2% of CKD patients with Medicare had claims for kidney disease education.**⁵⁶

Barriers to doctors helping people return to work include:⁵⁷

- Lack of medical school training in how to encourage people with chronic disease to work
- Confusion about what HIPAA law allows

⁵⁴ USRDS. 2016 ADR. Volume 2, ESRD, Table C.7

⁵⁵ USRDS. 2016 ADR. Volume 2, ESRD, Chapter 1 PowerPoint Slide #34. <https://www.usrds.org/2016/view/Default.aspx>. Accessed January 25, 2017

⁵⁶ USRDS. 2013 ADR. Volume 1, CKD, p. 117

⁵⁷ Denne J, Kettner G, Ben-Shalom Y. The role of the physician in the return-to-work process following disability onset. *Mathematica Policy Research*. March 2015. https://www.dol.gov/odep/topics/pdf/RTW_Role%20of%20Physician_2015-03.pdf. Accessed September 8, 2016

- Overcoming patients' views that having CKD requires avoidance of work and stress
- Addressing patient-employer relationships that may reduce motivation to work

The same study found that certain practices may help physicians to be more successful in helping patients keep their jobs:

- Promoting best practices and providing incentives
- Using organizations to educate physicians
- Encouraging physicians to use less medical jargon with patients
- Expanding Office of Disability Employment Policy (ODEP) resources, including:
 - Adding a section for physicians in the ODEP Toolkit⁵⁸
 - Identifying and reporting physician best practices re: patients' return to work
 - Providing guidelines to reconcile HIPAA & state workers' comp regulations
 - Adding education on return to work to medical school curricula and physician continuing education

Optimal Treatment of Anemia

In people with CKD, erythropoietin-stimulating agents (ESAs) are used to stimulate red blood cell production and offer at least partial relief of anemia symptoms such as fatigue.⁵⁹ However, we speculate that **current ESA prescription protocols that are appropriate for older and/or sedentary patients may not be sufficient to allow younger, active patients to keep their jobs.**

Patients should be informed of the potential risks and benefits of higher ESA doses. Just as importantly, patients should be informed about alternatives to ESA therapies, particularly blood transfusions, which can increase the occurrence of antibodies in a potential transplant recipient and make kidney transplantation—one of the most work-friendly treatment options—far more difficult. Figure 8 shows areas where treatment of anemia could be improved.⁶⁰

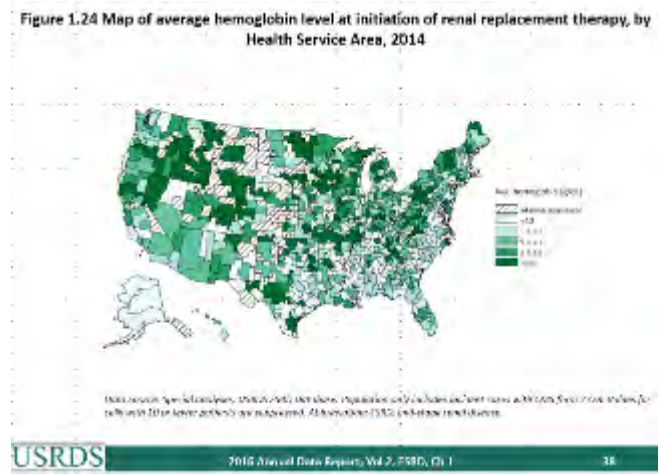


Figure 8: Average Hemoglobin at Initiation of Treatment for ESRD by Health Service Area

⁵⁸ Office of Disability Employment Policy Toolkit. <https://www.dol.gov/odep/return-to-work/> Accessed September 29, 2016

⁵⁹ Thamer M, Zhang Y, Kshirsagar O. Erythropoiesis-stimulating agent use among non-dialysis dependent CKD patients before and after the trial to reduce cardiovascular events with Aranesp therapy (TREAT) using a large US health plan database. *Am J Kidney Dis.* 2014 Nov; 64(5): 706–713

⁶⁰ USRDS. 2016 ADR. Volume 2, ESRD, Chapter 1, PowerPoint Slide #34. <https://www.usrds.org/2016/view/Default.aspx>. Accessed January 25, 2017

Optimal Team Management of Psychosocial Issues Related to CKD

Depression can affect ability to work—and a team approach to psychosocial care can help. African American hypertensive CKD patients who were depressed, unemployed, and who had lower income had lower health-related quality of life scores, while those with better coping skills and social support had better scores.⁶¹ This research as well as other research on use of a team approach, including physicians, nurses, social workers, and in some cases, pharmacists and physical therapists shows that working together can improve outcomes, even slowing the decline in eGFR.⁶² **A team approach to CKD education has helped CKD patients who were working 6 months prior to ESRD continue to work after starting dialysis.**^{63,64}

⁶¹ Porter A, Fischer MJ, Brooks D, Bruce M, Charleston J, Cleveland WH, Dowie D, Faulkner M, Gassman J, Greene T, Hiremath L, Kendrick C, Kusek JW, Thornley-Brown D, Wang X, Norris K, Unruh M, Lash J. Quality of life and psychosocial factors in African Americans with hypertensive chronic kidney disease. *Transl Res*. 2012 Jan;159(1):4-11

⁶² Bayliss EA, Bhardwaja B, Ross C, Beck A, Lanese DM. Multidisciplinary team care may slow the rate of decline in renal function. *Clin J Am Soc Nephrol*. 2011 Apr;6(4):704-10

⁶³ Rasgon S, Schwankovsky L, James-Rogers A, Widrow L, Glick J, Butts E. An intervention for employment maintenance among blue-collar workers with end-stage renal disease. *Am J Kidney Dis*. 1993 Sep;22(3):403-12

⁶⁴ Rasgon SA, Chemeski BL, Ho S, Widrow L, Yeoh HH, Schwankovsky L, Idroos M, Reddy CR, Agudelo-Dee L, James-Rogers A, Butts E. Benefits of a multidisciplinary predialysis program in maintaining employment among patients on home dialysis. *Adv Perit Dial*. 1996;12:132-5

Chapter 7: Recommendation—Educate Non-dialysis CKD Patients and Family Members to Maintain Employment

“What’s not unusual is the waxing and the waning of the symptoms. What’s not unusual are the internal debates. Can I show up [to work]? How will I feel when I show up? Who will show up? What kind of a person will I be?”

Rosalind Joffe

CKD and Work Education: Priorities of KidneyWorks Participants

The group agreed that patients require education about a variety of CKD-related topics as early and as often as possible—in settings that include healthcare clinics, schools, and workplaces—including creative support, to remain employed. Information, the group agreed, is best tailored to individual needs based on feedback from patients about their preferred learning styles, goals, symptoms, and concerns, and presented in a format (e.g., video, multimedia, websites, blogs, social media, telehealth, etc.) that is useful to the patient. Their consensus focused on the importance of:

- Education to self-manage CKD and associated comorbidities
- Information about treatments that will allow those with ND-CKD keep their jobs.
- Education for patients about employment laws that protect their rights
- Employment support and job coaching by vocational rehabilitation counselors and state employment office
- Mentoring and peer-to-peer programs
- Self-advocacy training and communication skills
- Identifying opportunities to create continuity of care and education for patients across the spectrum from early CKD to dialysis and transplant. Partner with healthcare providers and federal agencies:
 - National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK),
 - Health Resources and Services Administration (HRSA), and
 - National Kidney Disease Education clearinghouse.

Educate Family Members to Support Patient Employment

Family members and other social networks can provide vital support to people with CKD—or can persuade them that they are “too sick” to continue working. Thus, any educational efforts directed at patients must also include their support system, so they understand the benefits of helping patients keep working and do not sabotage patients’ efforts.

Educate Clinicians to Support Patient Employment

Medical appointments are usually during the work week. If there were options for evening or weekend appointments, CKD patients would not have to miss as much work, which might help them keep their jobs. Use of telemedicine allows physicians more leeway to see patients under certain circumstances without requiring an in-person office visit.

Patients can be motivated by physician advice. For example, in one study, patients whose doctors advised them to eat less fat, quit smoking or exercise before they received educational materials on these topics were significantly more likely to make changes in those behaviors than those who received materials without an accompanying doctor message.⁶⁵ Clinicians should educate patients and families about the benefits of maintaining employment and the risks/burdens of joblessness.

The KidneyWorks Stakeholder group noted that the American Society of Nephrology and the Renal Physicians Association have member newsletters that could be employed for outreach to nephrologists. Presentations at national meetings and peer reviewed and trade journal articles for clinicians at all levels (with continuing education credits) can be helpful as well.

Educate CKD Patients About Work-friendly Treatments for Kidney Failure

Since so many people with CKD quit their jobs within the last 6 months prior to kidney failure, it is vital for patients to learn that some treatment options for kidney failure are more work-friendly than others. Many work-friendly treatment options do not take time out of the work shift, do not cause debilitating symptoms, and allow people to have the mental and physical energy they need to be productive in the workplace. Education about the following treatment options may help patients feel more mentally prepared to keep their jobs:

- **Preemptive Kidney Transplantation.** A kidney transplant can be done *prior to* the need for dialysis, in medically appropriate CKD patients, particularly when a living donor is available, willing, and cleared for surgery. Obtaining a preemptive transplant can only occur when patients and their families know that this option exists—and many do not. Finding a suitable donor and having both donor and recipient undergo the extensive required medical and psychological testing takes time. In 2013, just 3,102 people had a transplant before they needed dialysis.⁶⁶ While survival may be the same as for transplantation after dialysis, preemptive transplant recipients have better long-term graft survival than those who were on dialysis even as little as a year.^{67,68} Plus, the ability to plan ahead and not need to arrange work around dialysis may help recipients of preemptive transplants to keep their jobs. The organization Donate Life America works to increase organ donation, as does the American Society of Transplant Surgeons.
- **Work-friendly Dialysis.** Patients may not know that some types of dialysis are more work-friendly than others. In the United States in 2014, 87.9% of people on dialysis went to a clinic three times a week for 3-4 hour hemodialysis treatments, typically during a typical 9-5

⁶⁵ Krueter MW, Chheda SG, Bull FC. How does physician advice influence patient behavior? Evidence for a priming effect. *Arch Fam Med.* 2000;9:426-33

⁶⁶ USRDS. 2016 ADR, Volume 2, ESRD, Table D.10

⁶⁷ Jay CL, Dean PG, Helmick RA, Stegall MD. Reassessing Preemptive Kidney Transplantation in the United States: Are We Making Progress? *Transplantation.* 2016 May;100(5):1120-7

⁶⁸ Grams ME, Chen BP, Coresh J, Segev DL. Preemptive deceased donor kidney transplantation: considerations of equity and utility. *Clin J Am Soc Nephrol.* 2013 Apr;8(4):575-82

workday.⁶⁹ After each treatment, they spend 2–12 hours recovering.⁷⁰ Both the schedule and the recovery time can make it difficult to maintain employment. There are several ways to do home dialysis, all of which are work-friendly. Only about 11.5 % of dialysis patients in 2014 did their treatments at home.⁷¹ Some clinics also offer in-center evening shifts and even overnight treatments that are far gentler on the body and don't take time out of the workday or require lengthy recuperation.

Advances in technology

Today is it easier for dialysis clinics and nephrology teams to conduct remote medical monitoring of patient treatments through home therapy machines—helping patients achieve more accurate treatments and better health outcomes. Advances in telemedicine, and important changes in Federal regulations including the Medicare Access and CHIP Reauthorization Act (MACRA) are allowing nephrologists the option to engage in telehealth—again allowing physicians to “see” patients virtually so patients can tailor dialysis to their work schedule as opposed to fitting their work schedule around dialysis.

Kidney organizations’ educational efforts

Several kidney organizations offer information about work-friendly treatments and working with kidney disease, such as the American Association of Kidney Patients (AAKP), Medical Education Institute (MEI), and the National Kidney Foundation (NKF).

Educate Employers about CKD

Employers may benefit from education about the benefits of retaining current employees—even with chronic illness—compared to the re-training costs in both dollars and institutional memory of hiring new ones.

Employers can also take steps to improve the chances of successful employment among those who are chronically ill. Offering flexible schedules and remote work options for appropriate jobs can allow workers to remain in contact with their coworkers and stay productive even if pain, fatigue, or other symptoms would make a commute and standard work day problematic.

Workplace Accommodations under the Americans with Disabilities Act (ADA)

The ADA applies to any employer with 15 employees and prohibits discrimination against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions, and privileges of employment.

Workplace accommodations can include making existing facilities used by employees readily accessible to and usable by an individual with a disability; restructuring a job; modifying work schedules; acquiring or modifying equipment; providing qualified readers or interpreters; or

⁶⁹ USRDS 2016 ADR. Volume 2, ESRD, Table D.11

⁷⁰ Rayner HC et al, 2014, IBID

⁷¹ USRDS. 2016 ADR. Volume 2, ESRD, Table D.11

appropriately modifying examinations, training, or other programs. Reasonable accommodation also may include re-assigning a current employee to a vacant position for which the individual is qualified, if the person is unable to do the original job because of a disability even with an accommodation. The Equal Employment Opportunity Commission enforces Title I (employment provisions) of the ADA.

<https://www.eeoc.gov/facts/fs-ada.html>

Chapter 8: Recommendation—Take Active Steps to Slow CKD Progression

People may not realize that symptoms they may have are caused by CKD,⁷² so even those who *are* diagnosed must be educated about *what* to watch for and report. There are many effective interventions to help slow CKD—which *can only be done by engaged patients themselves*—after they are informed by their clinicians—making education for *both* groups critical. These interventions include:

- **Blood Pressure Control.** A DASH-type diet high in fresh fruits and vegetables can lower blood pressure,⁷³ as can 61–90 minutes of exercise per week.⁷⁴ Medications help as well (if patients take them): in a randomized, controlled trial, kidney function declined significantly more slowly in the group that took ramipril, an ACE-inhibitor blood pressure pill.⁷⁵ Adding a second type of blood pressure medication (an angiotensin receptor blocker, or ARB) may have further benefit.^{76,77}
- **Blood Sugar Control.** Poor blood sugar control among people with diabetes raises the risk of CKD,^{78,79,80} and the poorer the blood sugar control, the higher the likelihood of kidney damage.^{81,82} Dietary fiber can help, found a meta-analysis of 15 randomized controlled trials,⁸³ and cinnamon may be of value as well.⁸⁴

⁷² Schatell D, Ellstrom-Calder A, Alt PS, Garland JS. Survey of CKD patients reveals gaps in knowledge about kidney disease. Part 1. *Nephrol News Issues*. 2003 Apr;17(5):23-6

⁷³ Salehi-Abargouei A, Maghsoudi Z, Shirani F, Azadbakht L. Effects of dietary approaches to stop hypertension (DASH)-style diet on fatal or nonfatal cardiovascular diseases—incidence: a systematic review and meta-analysis on observational prospective studies. *Nutrition*. 2013 Apr;29(4):611-8

⁷⁴ Ishikawa-Takata K, Ohta T, Tanaka H. How much exercise is required to reduce blood pressure in essential hypertensives: a dose-response study. *Am J Hypertens*. 2003 Aug;16(8):629-33

⁷⁵ The GISEN Group. Randomized placebo-controlled trial of effect of ramipril on decline in glomerular filtration rate and risk of terminal renal failure in proteinuric, non-diabetic nephropathy. *Lancet*. 1997 June 28;349(9069):1857-63

⁷⁶ Schreiber MJ Jr. Preventing renal disease progression: can complete renin-angiotensin aldosterone blockade work? *Cleveland Clinic J Med*. 2008;75(10):699-704

⁷⁷ The Remission Clinic Task Force. The Remission Clinic approach to halt the progression of kidney disease. *J Nephrol*. 2011;24(03):274-81

⁷⁸ TODAY Study Group. Rapid rise in hypertension and nephropathy in youth with type 2 diabetes: the TODAY clinical trial. *Diabetes Care*. 2013 Jun;36(6):1735-41

⁷⁹ Kundu D, Roy A, Mandal T, Bandyopadhyay U, Ghosh E, Ray D. Relation of microalbuminuria to glycosylated hemoglobin and duration of type 2 diabetes. *Niger J Clin Pract*. 2013 Apr-Jun;16(2):216-20

⁸⁰ Ahmed AA, Alsharief E, Alsharief A. Intensive versus conventional glycemic control: what's best for patients with type 2 diabetes? *Diabetes Metab Syndr*. 2013 Jan-Mar; 7(1):48-51

⁸¹ The DCCT/EDIC Research Group. Intensive diabetes therapy and glomerular filtration rate in type 1 diabetes. *N Engl J Med*. 2011 Dec. 22;365(25):2366-76

⁸² Coca SG, Ismail-Beigi F, Haq N, Krumholz HM, Parikh CR. Role of intensive glucose control in development of renal endpoints in type 2 diabetes: systematic review and metaanalysis. *Arch Intern Med*. 2012 May 28;172(10):761-9

⁸³ Post RE, Mainous AG 3rd, King DE, Simpson KN. Dietary fiber for the treatment of type 2 diabetes mellitus: a meta-analysis. *J Am Board Fam Med*. 2012;25:16-23

⁸⁴ Davis PA, Yokoyama W. Cinnamon intake lowers fasting blood glucose: Meta-analysis. *J Med Food*. 2011 Sep;14(9):884-9

- **Exercise.** Promoting physical activity among people with CKD can help improve their overall health and reduce the risk that CKD will progress.⁸⁵ In fact, each 60 minutes spent exercising was associated with a 0.5% slower decline in eGFR per year.⁸⁶
- **Weight Loss.** Weight gain is linked with diabetes and high blood pressure, and is a risk factor for CKD.^{87,88,89} Almost two-thirds of American adults have BMI's over 25 (overweight), and, of these, half are obese, with BMI's greater than 30.⁹⁰ Weight loss helps reduce both BMI and protein in the urine.⁹¹ In fact, one analysis found that each kilogram (2.2 lbs.) of weight loss predicted a significant 110 mg drop in proteinuria.⁹²
- **Eating Less Protein.** Kidneys excrete byproducts of protein metabolism. Compared to a higher protein diet, a lower protein one created less protein wastes after 6-18 months, and study participants who ate this way needed fewer medications.⁹³ But, this is a difficult diet for many Americans to follow.
- **Smoking Cessation.** In a prospective study of 7,476 subjects, one pack of cigarettes/day raised the risk of microalbuminuria by 92%, and reduced kidney function by 53%.⁹⁴ Thus, quitting may help. Computer-based interventions have helped in smoking cessation.⁹⁵
- **Avoiding/Limiting Non-Steroidal Anti-Inflammatory (NSAID) Pain Medications.** Some studies have linked these common over-the-counter pain pills with CKD.⁹⁶ It seems prudent to use the lowest effective dosage or use other pain medications to avoid possible kidney damage.

⁸⁵ Umpierre D, Ribeiro PA, Kramer CK, Letao CB, Zucatti AT, Azevedo MJ, Gross JL, Ribeiro JP, Schaan BD. Physical activity advice only or structured exercise training and association with HbA1c levels in type 2 diabetes: a systematic review and meta-analysis. *J Amer Med Assoc.* 2011 May 4;305(17):1790-9

⁸⁶ Robinson-Cohen C, Littman AJ, Duncan GE, Weiss NS, Sachs MC, Ruzinski J, Kundzins J, Rock D, de Boer IH, Ikizler TA, Himmelfarb J, Kestenbaum BR. Physical activity and change in estimated GFR among persons with CKD. *J Am Soc Nephrol.* 2014;25:399-406

⁸⁷ Wahba I, Mak R. Obesity and obesity-initiated metabolic syndrome: Mechanistic links to chronic kidney disease. *Clin J Am Soc Nephrol.* 2007;2:550-62

⁸⁸ Wang Y, Chen X, Song Y, Caballero B, Cheskin LJ. Association between obesity and kidney disease: A systematic review and metaanalysis. *Kidney Int.* 2008;73:19-33

⁸⁹ Hall JE, Crook ED, Jones DW, Wofford MR, Dubbert PM. Mechanisms of obesity-associated cardiovascular and renal disease. *Am J Med Sci.* 2002;324:127-37

⁹⁰ Ogden CL, Carroll MD, Curtin LR, McDowell MA, Tabak CJ, Flegal KM. Prevalence of overweight and obesity in the United States, 1999-2004. *J Amer Med Assoc.* 2006;294:1549-55

⁹¹ Navaneethan SD, Yehnert H, Moustarah F, Schreiber MJ, Schauer PR, Beddhu S. Weight loss interventions in chronic kidney disease: A systematic review and meta-analysis. *Clin J Am Soc Nephrol.* 2009;4:1565-74

⁹² Afsinnia F, Wilt TJ, Duval S, Esmaili A, Ibrahim HN. Weight loss and proteinuria: a systematic review of clinical trials and comparative cohorts. *Nephrol Dial Transplant.* 2010;25:1173-83

⁹³ Cianciaruso B, Pota A, Torraca S, Anecchini R, Lombardi P, Capuano A, Nazzaro P, Bellizzi V, Sabbatini M. Metabolic effects of two low protein diets in chronic kidney disease stage 4-5—a randomized controlled trial. *Nephrol Dial Transplant.* 2008;23:636-44

⁹⁴ Pinto-Sietsma SJ, Mulder J, Janssen WM, Hillege HL, de Zeeuw D, de Jong PE. Smoking is related to albuminuria and abnormal renal function in nondiabetic persons. *Ann Intern Med.* 2000 Oct 17;133(8):585-91

⁹⁵ Chen YF, Madan J, Welton N, Yahaya I, Aveyard P, Bauld L, Wang D, Fry-Smith A, Munafo MR. Effectiveness and cost-effectiveness of computer and other electronic aids for smoking cessation: a systematic review and network meta-analysis. *Health Technol Assess.* 2012;16(38):1-205

⁹⁶ Kuo HW, Tsai SS, Tiao MM, Liu YC, Yang CY. Analgesic use and the risk for progression of chronic kidney disease. *Pharmacoepidemiol Drug Saf.* 2010 Jul;19(7):745-51

Chapter 9: Recommendation—Support People with Non-dialysis CKD in the Workforce, Including Kidney Transplant Recipients

“If I worked construction and both my arms are broken, you wouldn’t expect me to work construction. In the past...my cognitive skills were compromised...I couldn’t think. Shortly after my transplant, my cognitive skills improved more than my physical skills...I wanted to work and it’s the work that we have to do to get the job done. There are so many more patients who need our assistance. We can benefit and will benefit as we work out ways to make things better.”

Richard Knight

Interventions that Work

Certain interventions have been shown to help support employment after receipt of a new kidney, including:⁹⁷

- **Improving Patient Self-perceptions of Health.** Living with others who encourage working, and helping patients to feel more confident and not “disabled” made it more likely that people would continue working or return to work after a transplant. Feeling physically and emotionally healthy matters, and patients who did not need job accommodations were more likely to work.
- **Identifying Meaningful Work.** Workers with more post-secondary education were more likely to be employed post-transplant. The feeling that work provides a sense of purpose—not just a paycheck—made a difference in whether people worked.
- **Encouraging Employer Flexibility.** Being able to return to a previous job where an employee had known value was easier than trying to find a new job. Employers who provide openness to employee needs, flexibility, and time off for medical appointments improved patients’ ability to stay employed.
- **Providing Vocational Support.** Rehabilitation programs focusing on return to work and retraining if necessary and communication between the transplant team and a current or prospective employee can help connect the dots between employee abilities and needs and the workplace.

Stay at Work/Return to Work (SAW/RTW) for Workers with Injuries or Chronic Illness

Mathematica, which has written multiple policy papers for the SAW/RTW collaboration, recommends that **“evidence-based early intervention” (EBEI) programs be offered to target populations who have jobs and are most likely to keep working if they have the services they need at the right time.**⁹⁸ These services could include such things as healthcare; rehabilitation; coordination with workers, employers, providers, and even financial help to prevent financial

⁹⁷ Chang CF, Winsett RP, Gaber AO, Hathaway DK. Cost-effectiveness of post-transplantation quality of life intervention among kidney recipients. *Clin Transplant*. 2004 Aug;18(4):407-14

⁹⁸ Stapleton D, Burns R, Doornink B, Harris M, Anfield R, Cashdollar W, Gifford B, Ufier K. Targeting early intervention to workers who need help to stay in the labor force. October 2015. https://www.dol.gov/odep/topics/pdf/SAW-RTW_Early%20Intervention_FINAL_2015-10.pdf. Accessed September 2, 2016

stress leading to job loss. Common characteristics of individuals who could benefit from EBEI include those with limited access to the services they need, who have a likelihood of going on SSDI *without* those services, and who have a likelihood of staying in the workforce *with* services. Mathematica recommends who should be targets for EBEI services and those who should not receive them in Table 5. Transplant recipients are eligible for disability for one year post-transplant. However, if offered Stay at Work services like EBEI, those who receive a transplant may be able to take a brief medical leave and perhaps receive rehabilitation services, if necessary. Short-term financial help through EBEI could help reduce financial hardship during a leave since the Family and Medical Leave Act may be unpaid time off work. This might help workers with a transplant avoid applying for disability.

Table 5: Mathematica Policy Research Targets and Non-targets for Evidence-based Early Intervention (EBEI) Services

Targets for EBEI Services	EBEI Services Would <i>Not</i> be Recommended
Have chronic conditions that EBEI services could help manage	Are expected to have continuous deterioration, untreatable symptoms, and unavoidable side effects
Have limited education and income	Have difficulty concentrating or impaired thinking with fatigue
Have limited access to quality healthcare or difficulties using the healthcare system	May be harmed by EBEI services
Work in small or medium sized businesses	No evidence that a program will help.

Stable ND-CKD patients who do not have other serious comorbidities, including transplant recipients, would appear to meet criteria for EBEI program services if services are available. Those patients with more rapidly progressing ND-CKD may or may not be good candidates for EBEI services.

Factors that Help ND-CKD Patients Work, Including Those with Transplants

- Identifying motivators for work
- Providing appropriate care for medical and mental health conditions and chronic illness requiring following a treatment plan
- Providing financial help if needed during a brief work leave of absence

SECTION 3: KIDNEYWORKS AGENDA & NEXT STEPS

Chapter 10: KidneyWorks Policy Agenda

Policy Focus of Kidney Works Participants

How can policymakers ensure that people with chronic kidney diseases and other chronic conditions can continue to work? The group consensus was to:

- Provide coverage in all insurance plans for early CKD screening of those at risk.
- Promote home dialysis—both hemodialysis and peritoneal dialysis—through fair reimbursement policies.
- Offer incentives to insurance companies, providers, patients, and businesses to make it financially feasible to hire and retain employees with chronic illnesses.
- Include education about the needs of CKD patients and implications of disability in training for vocational rehabilitation counselors, social workers, physicians.
- Create incentives for employers to offer mentoring and workplace job coaching.
- Provide tax credits for employers of any size to make accommodations, including telework available for those with chronic illnesses as well as those with disabilities.
- Develop a national education campaign for employers and employees to explain the Americans with Disabilities Act, the Family and Medical Leave Act, and to debunk myths that would prevent an employer from hiring someone with a chronic illness.

For Patients:

- Those with known CKD should ask their primary care physician for a referral to a nephrologist; seek out CKD education, support, and resources; and participate in and follow their treatment plans.
- Those who do not know if they have CKD should ask for copies of laboratory test results, track them over time, and ask about any high or low results.

For Employers:

- Allow flex-time or time off for medical appointments to promote better employee health.
- Retain employees who have CKD to avoid the high costs of hiring and training new employees, many of whom will *also* have one or more chronic illnesses—as half of all Americans do.

For Medical/Professional Societies:

- Consider developing performance measures to support patient employment throughout CKD.
- Examine models used by other countries that maintain patient employment despite advancing CKD or other chronic illnesses, and determine whether those models can be used or adapted for the U.S.
- Increase nephrology fellows' awareness of the challenges faced by employed patients—and the many benefits to patients and their families—and society—of continuing to work with ND-CKD.

For Healthcare Providers:

- Offer appointment times that accommodate patients' work schedules.
- Talk with patients and families about the benefits of working and avoiding disability when possible.
- Remember that patients who can keep their jobs are more likely to retain employer group health plans that will bring in more revenue to a practice or clinic than Medicare or Medicaid.
- Consider the societal benefits of a healthier population with fewer hospitalizations, less anxiety and depression, and a more active lifestyle.

For Policymakers/Congress:

- Recommend that government and private health plans cover early CKD screening of those who are at increased risk of progression according to KDIGO guidelines.
- Encourage insurance companies, providers, and businesses to make it financially feasible to hire and retain employees with chronic illnesses, including ND-CKD.
- Promote training for vocational rehabilitation counselors, social workers, and physicians that includes education about the unique needs of CKD patients who want to keep their jobs.
- Consider providing tax credits for employers of *any* size to make accommodations, including telework when feasible, for those with chronic illnesses and disabilities.
- Develop a national education campaign for employers and employees to explain the Americans with Disabilities Act and the Family and Medical Leave Act, and to debunk myths about hiring and retaining employees with a chronic illness.
- Consider amending the Medicare Improvements for Patients and Providers Act (MIPPA) to expand qualified CKD education providers to include clinical social workers and add employment as a topic.
- Consider expanding Kidney Disease Education (KDE) Services under MIPPA to include any Medicare patient diagnosed with CKD, not just Stage 4.
- Study the feasibility of expanding the Family Medical and Leave Act to additional employers and encouraging employers to continue to pay workers during a medical leave of absence.

For Other Federal Agencies:

- **Centers for Disease Control and Prevention (CDC):**
 - Expand the Kidney Disease Initiative to include a public outreach campaign coordinating with the Public Health Services.
 - Study geographic disparities in the prevalence and incidence of both CKD and ESRD.
- **Centers for Medicare & Medicaid Services (CMS):**
 - Collect data on employment up to 5 years prior to ESRD and include the *type* of job (e.g., sedentary, active, mixed) on Form CMS-2728 (ESRD Medical Evidence Report).
 - Reimburse physicians, non-physician providers, and CKD healthcare teams to discuss goals, employment benefits, and barriers with their patients and work together to overcome them.

- Provide sufficient reimbursement to motivate registered dietitians and clinical social workers to become Medicare providers so they be reimbursed for seeing ND-CKD patients prior to ESRD. Registered dietitians who are Medicare providers can provide diabetes self-management education for those with diabetes and medical nutrition therapy for those with 50% kidney function or less with physician referral.
- Include in the USRDS contract a study of the barriers to utilization of Medicare's Kidney Disease Education Services.
- **National Institutes of Health (NIH):** Designate funding to support CKD research projects that include employment as a variable.
- **Department of Labor (DOL):** Provide evidence-based early intervention services to working people with stable CKD, including transplant recipients.
- **Rehabilitation Services Administration (RSA):** Study what is needed (services and/or equipment) to help state vocational rehabilitation agencies help people with ND-CKD keep their jobs.

Chapter 11: KidneyWorks Research Agenda

Currently, de-identified, patient-level data are being collected by nephrology practices and dialysis providers, insurance companies, various government agencies and contractors. However, much of these data focus on kidney failure. Perhaps more can be found in the future from Accountable Care Organizations (ACOs) or other creative models of care that include non-dialysis CKD (ND-CKD) patients and those with kidney transplants. The KidneyWorks group agreed that more data are needed on CKD patients to explore quality of life, employment or education, and solutions to barriers created by healthcare providers, insurance companies, and government agencies.

Specific questions raised by the KidneyWorks group that could be answered by research included:

CKD Demographics and Employment

- Are CKD employment data being collected somewhere, such as large health plans or self-insured companies, and not disseminated widely enough for generalized application to relevant research questions concerning employment maintenance and CKD?
- Are there differences in disability rates for white collar vs. blue collar labor?
- Can we build a predictive model of which CKD patients are at risk for disability?
- Are there regional differences in type of workforce, availability of jobs, discrimination?
- Can best practices in CKD employment be identified by collecting, analyzing, and comparing employment outcomes among healthcare providers?

Patients

- What performance measures concerning employment are meaningful to *them*?
- What are the relative contributions of CKD itself and related comorbidities to work-limiting symptoms?
- At what stage of kidney disease do CKD patients quit work—and why?
- What is the relationship between use of the Family and Medical Leave Act time off and quitting employment? Do those who use FMLA return to work more often than those who don't? Why or why not?

Clinicians

- At what point—if ever—do clinicians discuss employment with working CKD patients?
- What are medical professionals' knowledge, beliefs and attitudes about patients working?
- What do healthcare professionals who work with non-dialysis CKD patients know about the implications of disability and the laws that protect workers with disabilities?

Employers

- How do we motivate and educate employers to encourage them to retain employees with CKD?
- Would looking at insurance companies' or hospitals' data help to develop an employer-business case supporting CKD employee retention?
- What are relevant state and federal laws that promote employment of people with chronic illnesses?

Interventions

- Which interventions are most effective in maintaining employment in different populations and stages of CKD?
- Are there incentives/disincentives for vocational rehabilitation offices to work with ND-CKD patients to help them keep their jobs? What interventions would reduce disincentives?
- How can regular assessment of ND-CKD patients using the Kidney Disease Quality of Life physical and mental functioning survey inform employment-retention strategies?

Chapter 12: KidneyWorks Next Steps

Identify Funding Support from Industry

The incentives and goals described in this report will have a significant impact on the quality of life and treatment outcomes for patients with CKD. Finding a way to convert these goals into realistic projects and community-based research will require funding from several sources. With adequate funding, the next steps of KidneyWorks will follow a deliberate strategy designed to leverage the respective reach and relationships of roundtable participants as well as the larger community of patients and professionals both within and beyond the kidney community.

Develop Outreach Materials and Messaging

Creating materials and messaging for the various audiences who can influence CKD patient employment will facilitate dissemination. Examples suggested by the KidneyWorks participants included a KidneyWorks logo and graphics, posters, infographics, public service announcements, publications (newsletters, handouts, professional journal articles, human resource newsletters, employee newsletters, printed inserts for products such as medications), and a phone app. Materials may be needed in more than one language. Product tie-ins and partnerships may be useful as well.

Collaborate with Other Chronic Disease Organizations to Boost Employment

CKD is not the only chronic condition that can make continued employment challenging. Many other illnesses, from diabetes to multiple sclerosis have challenges of their own, and collaborating to put the dignity of employment on the agenda can benefit even more Americans. Organizations that represent people with chronic diseases are well-positioned to advocate for their members' needs, including such topics as the use of health-related quality of life as an outcome measure, and development of new, patient experience of care measures that include employment. The HR departments of large employers, for example, may be able to offer workplace coaching for people with chronic illness, just as they do for those with substance abuse or other problems through company employee assistance programs (EAP).

Develop a Business Case for Employers

Long-term employees have value, in terms of knowledge of the business and its customers, a specific skill set, and the high costs of hiring, training, and retaining new staff. Creating a business case outlining the benefits to employers of keeping people who have chronic illnesses will facilitate communication with this key audience. A business case would also address myths about hiring people with chronic illnesses, and would provide information about current hiring incentives that employers may not be aware of. Small vs. large employers may each require a separate business case.

Include Employment in Health Professionals' Clinical Curricula/Continuing Education

Chronic illnesses are often treated as if their effects are strictly clinical, when, in fact, an illness can affect *every aspect of day-to-day life*, including sleeping, eating, energy level, pain, mobility, appearance, time management, and ability to think clearly—several of which have an impact on employment. Clinicians of all kinds, from physicians to physical therapists need to consider the lifestyle implications of illness and specifically ask patients about their priorities, including work. Offering continuing education (CE)/continuing medical education (CME) credits to healthcare providers for presentations and other CE/CME vehicles is a time-honored and effective way to ensure that they are interested in this vital topic.

Create a Patient Website and Toolkit

The KidneyWorks meeting participants agreed that a key future task will be to build a toolkit to empower patients to keep their jobs. Such a toolkit could be offered to patients by a variety of organizations, agencies and companies, with materials that could include (depending on resources), but not limited to:

- An algorithm, flow chart or step-by-step diagram for vocational rehabilitation counselors and healthcare professionals to help non-dialysis CKD (ND-CKD) patients keep their jobs
- Case studies and/or personal stories
- Information to help patients understand CKD and slow their progression
- Employment tools and resources, including peer mentorship opportunities, lists of chronic disease-friendly employers
- Opt-in text messaging to support medication adherence, exercise, etc.
- Online or telephone access to a dietitian, social worker, exercise physiologist, psychologist, and/or work coach
- Phone app to educate and address barriers non-dialysis CKD patients have around work
- Video conversation guides to help patients talk to their family members, clinicians, and employers
- Friendly competitions between toolkit recipients to improve lifestyle
- Implementation strategies for tool kit utilization, including performance measurement for monitoring improvement in employment maintenance, and avoidance of unintended consequences.

In addition to incorporating social media into a toolkit, the group suggested identifying working age people with CKD who are employed full- or part-time to start hashtags on Twitter and make videos to share on YouTube.

Develop Pilot Projects

Some of the KidneyWorks participants expressed an interest in testing the ability of CKD disease management companies to help patients maintain their employment by implementing some of these suggestions. Such pilot projects have the potential to collect data that could be useful for a larger and longer term research study, and to inform our efforts to improve outcomes in this vital area.

Conclusion

Kidney disease is both costly and devastating, but non-dialysis chronic kidney disease (ND-CKD) does *not* have to mean permanent disability. Working-age Americans who are diagnosed with CKD can have far greater independence to pursue their aspirations, achieve better health outcomes and contribute more fully to their families and society if they are able to slow the progression of their disease and stay employed. ***Barriers to their desire and ability to keep working must be identified and removed.***

KidneyWorks seeks to reduce disability and dependency and help people with ND-CKD remain active, productive, taxpaying citizens by taking proactive steps to educate patients, families, clinicians, and lawmakers and enact work-friendly practices and policies. **ND-CKD patients who continue to work help themselves, their families, their healthcare providers, the healthcare industry in general, insurers, employers, taxpayers—and the U.S. government.** (See a table of who benefits on Page 8-9.)

This document represents the culmination of the Phase 1 KidneyWorks Stakeholders' meeting. With financial and other support from the current and future stakeholders, Phases 2 and 3 will include the development of strategies, tactics, and resources to make working with CKD more possible.

SECTION 4: APPENDICES

APPENDIX A: List of Acronyms and Definitions

AAKP—American Association of Kidney Patients, a nonprofit organization dedicated to improving the quality of life for kidney patients through education, advocacy, and the fostering of patient communities. AAKP and MEI are collaborating on the KidneyWorks initiative.

ACR—urine albumin-to-creatinine ratio, also UACR; this test measures the amount of albumin in the urine; greater than 30 g/ml can indicate kidney damage

Albumin—a type of protein that is measured in the urine to assess for kidney damage

BLS—Bureau of Labor Statistics

CDC—Centers for Disease Control and Prevention

CKD—chronic kidney disease

CMS—Centers for Medicare & Medicaid Services

Creatinine—a waste formed by muscle movement that is removed by healthy kidneys

Dialysis—the process of removing wastes and excess water from someone with kidney failure by diffusion across a semi-permeable membrane through hemodialysis or peritoneal dialysis using different treatment schedules in the home or in a dialysis facility

eGFR—estimated glomerular filtration rate, see glomerular filtration rate

EPO—erythropoietin

Erythropoietin—a hormone made by healthy kidneys that tells the bone marrow to make new red blood cells

ESA—erythropoietin stimulating agent; a medication to trigger red blood cell production

ESRD—end stage renal disease (kidney failure)

FDA—Food and Drug Administration

Glomerular filtration rate—a measure that approximates the percent of kidney function based on age, gender, race, and results of a blood test for serum creatinine

HRQOL—Health-related quality of life, a measure of physical and mental functioning, burden and effects of kidney disease, and symptoms; results predict hospitalization and death

Kidneys—organs that keep balance in the body by removing wastes and extra water, keeping substances in the blood in a tight range, controlling acid-base balance and blood pressure, and releasing hormones

Kidney Transplant—surgery to place a healthy kidney from a living or deceased donor into someone whose kidneys have failed

MACRA—Medicare Access and CHIP Reauthorization Act (2015) changed how physicians are paid, reauthorized the Children’s Health Insurance Program, encouraged case management, use of telehealth, and providing timely health information to patients

MEI—Medical Education Institute, a nonprofit organization that helps people with chronic disease learn to manage and improve their health

MIPPA—Medicare Improvement for Patients & Providers Act (2008) funded state health insurance assistance programs to help people with Medicare understand their insurance options and established the Medicare drug program (Part D) and provided funding for Medicare savings programs to help people with limited income pay for healthcare

ND-CKD—non-dialysis-dependent CKD, for the purposes of KidneyWorks, people with stage 3-5 chronic kidney disease who are not on dialysis, including those with a functioning kidney transplant

NIDDK—National Institute of Diabetes and Digestive and Kidney Diseases

SSDI—Social Security Disability Insurance – a cash benefits disability insurance program available to workers who have accumulated enough work quarters by age to qualify

SSI—Supplemental Security Income – a means-tested disability program for those who are very low-income and disabled, and may never have worked

UNOS—United Network for Organ Sharing; which matches donated kidneys to recipients

USRDS—United States Renal Data System; a compendium of kidney disease data compiled by the University of Michigan under a CMS contract

Working Age—18 through 64 for the purpose of KidneyWorks, although many people work outside this range

APPENDIX B: History of Early Dialysis

The First Hemodialysis Machine

The first “rotating drum” machine used to perform hemodialysis on people with acute (sudden onset) kidney failure was built by Dutch physician Willem Kolff. The doctor passed blood from a patient’s wrist through sausage casings, which were semipermeable, allowing kidney toxins to pass out of the blood and into a salt water bath which was agitated by a rotating drum. Kolff used a coupling similar to those on water pumps used in Ford cars to return the blood to the patient. While his first 15 patients did not survive, in 1945 a 67-year-old woman in a coma awakened after longer treatments than Kolff had given the prior patients, and lived for 7 more years.⁹⁹ As a fresh vein and artery were used for each dialysis treatment and had to be tied off afterward, there simply were not enough appropriate blood vessels to perform more than about a half dozen treatments. Here is a picture of the Kolff machine.¹⁰⁰



Reaching the Blood for Hemodialysis

Nils Alwall of Sweden used a hemodialysis access made from glass to dialyze 1,500 patients between 1946 and 1960. Drs. Belding Scribner and Wayne Quinton in Seattle modified the device to create a Teflon “shunt,” using one tube sewn to an artery, a second tube sewn into a vein, and a connector to the machine.¹⁰¹ The Scribner shunt made chronic hemodialysis possible. This photograph was taken at the Dialysis Museum at Northwest Kidney Centers in Seattle.



The First Dialysis Patient

In 1960, a 42-year-old machinist named Clyde Shields became the first chronic hemodialysis patient at University Hospital in Seattle, followed by three others, one of whom died within months. At the time, the National Institutes of Health funded the experimental treatment. Dr.

⁹⁹ Blakeslee S. Willem Kolff, Doctor Who Invented Kidney and Heart Machines, Dies at 97. *New York Times*. February 12, 2009. <http://www.nytimes.com/2009/02/13/health/13kolff.html>. Accessed September 5, 2016

¹⁰⁰ Home Dialysis Central, Home Dialysis Museum. [http://homedialysis.org/home-dialysis-basics/machines-and-supplies/dialysis-museum#prettyPhoto\[museum-gallery\]/0/](http://homedialysis.org/home-dialysis-basics/machines-and-supplies/dialysis-museum#prettyPhoto[museum-gallery]/0/). Accessed September 5, 2016

¹⁰¹ Blagg CR. 2007. Ibid

Belding Scribner successfully sought funding from the Hartford Foundation and established Seattle Artificial Kidney Center (SAKC), the first non-profit chronic hemodialysis clinic, with three beds.¹⁰² Now that chronic hemodialysis was possible, there were more individuals with CKD who wanted to receive the costly treatment and live than there were machines or resources to treat them. Who would decide which candidates would receive dialysis and which would be managed without until natural death occurred?

The “Life or Death” Committee

The story of how difficult decisions were made about how to allocate the scarce resource of dialysis and who made them was published in an article in *Life Magazine*.¹⁰³ Five patients received dialysis at a cost of \$15,000 each annually as a trial to see if the treatment would be effective and could be feasibly be offered nationally. In 1961 SAKC set up an Admissions and Policies Committee and the King County Medical Society chose seven anonymous members: a housewife, minister, banker, lawyer, labor leader, state government official, and a surgeon. Collectively, the group became known as the “Life or Death Committee.” Committee members did not know the patients’ names or meet them; they reviewed the records for patients that doctors had pre-screened for psychological and medical suitability.

The factors the committee considered were age, sex, marital status, number of dependents, income, assets, coping, education, occupation, future potential, references, and residence in Washington State. They wrote bylaws: Children and those over age 45 were automatically excluded. The article related discussions of five of the candidates for the two machines—a housewife with two children, an aircraft worker with six children, a chemist with three children, an accountant with three children, and a small businessman with three children. The accountant and the chemist were not selected because their accumulated wealth would keep their families from being “a burden on society.” The housewife was not selected because she lived too far away. In the end, the aircraft worker whose company would help him rehabilitate and the small businessman who was active in his church were selected. Each member of the committee was interviewed for the story and they shared their thoughts about the process. All quotes below are from the *Life Magazine* article.

The lawyer explained:

“When I was first invited to be on this committee, I said I would prefer not to serve. But I knew I was capable and I felt I would be impartial...The so-called rejected patients would have died with or without the committee—as, of course, we all will some day. I cannot honestly say I am overwrought by the plight of the patients we do not choose—the ones we choose have an awfully rugged life to look forward to. Not all men would wish it.”

¹⁰² Blagg CR. 2007. Ibid

¹⁰³ Alexander S. They Decide Who Lives, Who Dies. *Life*. Vol. 53(19), November 9, 1962

The minister was distressed:

"After our first meeting, I was very bothered. I felt I was forced to make decisions I had no right to make and I felt that, of necessity, our selections would have to be made on the basis of inadequate information...The principle of this thing has bothered me more than the practice...Would I want to take this treatment, if it became a medical necessity for me? My job is to help people from a set of life values. And to help them accept the fact that, like birth, death is part of life—not, wham, the door slams!"

The homemaker noted:

"So it is wonderful for me to have a chance to help in a real breakthrough...This treatment works! That gives me terrific hope. I realize the doctors must use people, not animals, for this research, and I think in a funny way that actually helps me to serve on the committee...We always have the hope that by some miracle the facilities can be enlarged in time to save the patient who has some chance of living longer without this treatment."

The banker found a way to rationalize his experience:

"...I do have reservations about the moral aspects, the propriety of choosing A and not B, for whatever reason. I have often asked myself—as a human being, do I have that right? I don't really think I do. I finally came to the conclusion that we are not making a moral choice here—we are picking guinea pigs for experimental purposes. This happens to be true; it also happens to be the way I rationalize my presence on this committee. The situation, as I see it, is life and death, complicated by limitations of money. We send billions of dollars overseas to people we know nothing about, many of whom despise us. If Congress or somebody wanted to provide the money, we could take care of all our kidney people."

Said the state official:

"The central problem here is that medicine has moved forward so rapidly it has advanced beyond the community's support. Our committee must try to bridge the gap...We have forced ourselves to make life or death decisions on a virtually intuitive basis. I do have real faith in the ability of kindly, conscientious, intelligent people to do a good job [choosing which live and which die] guided simply by their instincts, but we ought not to go on this way...The resources of the human spirit in adversity are truly remarkable. These people can face more than we give them credit for."

The labor leader explained his criteria:

"The way I look at it, if the Seattle trial is to be a pilot for other committees, we cannot afford any human failures. Also, we just haven't got the funds. So I want to pick the man with the most will power, the fellow who is least likely to give

up...A man's job, his education, his wealth—that means nothing to me. But I do think a man ought to have some religion, because that indicates character. And I imagine a large family would be a great help—a lot of kids help keep a man from letting down, even when the going gets rough. The wonderful thing to me about this work is that we are finally past the stage of experiment. We know we can prolong life...I believe we can eventually take care of everybody.”

The surgeon's comments were prescient:

“...this project will not just benefit one disease—it will benefit all aspects of medicine. We are hoping someday to learn how to transplant live organs. So far, the body will not accept foreign tissue from another person, but eventually we will find a way to break this tissue barrier. Meanwhile I serve on this committee not as a doctor but as a citizen and, I hope, a humanitarian...I can tell you this: I do sleep better at night after deciding on one of these committee cases than I sleep after deciding a case of my own...I sometimes hear via the grapevine when a patient whom we passed over dies...there always comes a feeling of deep regret, and then that dreadful doubt—perhaps we chose the wrong man. One can just never face these situations without feeling a little sick inside.”

About John Myers, one of the first dialysis patients, and a subject of the *Life Magazine* article, author Shana Alexander reported that he described himself starting dialysis:

“My skin had turned a funny, dark-gray color, my eyes were pink, and I was so swollen I had no chin at all. I looked exactly like a very sick seal.”

Soon after starting dialysis, Alexander noted, he went back to work for an hour a day, and eventually, by the time the article was written, he was working 7 hours a day.

Myers later elaborated:

“Of course I never feel like running a race or staying up all night...Like all the patients, I still have high blood pressure, and I still get tired easily. But at least I'm like other people again...”

In 1965 NBC showed a documentary entitled *Who Shall Live?*¹⁰⁴ This film brought dialysis and the decisions that had to be made for real people with kidney failure, including the “Life or Death Committee” into people's living rooms, stirred criticism and controversy, sparked a new field of bioethics, and eventually pressured the federal government to act. In 1963, the United States Veteran's Administration (VA) set up dialysis in 30 VA hospitals, while other federal agencies provided grant funding for additional research programs. In 1967, the Committee on Chronic Kidney Disease that had met for two years recommended that Medicare pay for dialysis and kidney transplantation. The report was championed by Senator Henry Jackson (D-WA) who had a friend on dialysis. Starting in 1965, Sen. Jackson introduced a bill to pay for dialysis and

¹⁰⁴ NBC. “Who Shall Live?” <https://www.youtube.com/watch?v=FMay5zw1loA>. Accessed September 5, 2016

kidney transplantation at every session of Congress. The National Kidney Foundation hired a lobbyist to help with the push to pass legislation.

In November 1971, when the White House and Congress discussed national health insurance, Shep Glazer, vice president of the National Association of Patients on Hemodialysis (now the American Association of Kidney Patients) dialyzed briefly in the United States Congress on the floor of the Members and staff of the powerful U.S. House Ways and Means Committee—an event that was widely reported in the press and is still talked about today. In December 1971, House Ways and Means Committee Chairman Wilbur Mills (D-Arkansas), introduced a bill in the House and United States Senator Vance Hartke (D-Pennsylvania) introduced one in the Senate to expand Medicare coverage to those patients suffering from chronic kidney disease as part of the Social Security Amendments of 1972. Chairman Mills had been personally impacted by stories of those whose lives had been extended by dialysis in his state, including that of a businessman whose family (including his son Mr. Robert Abbott of Little Rock) had purchased a machine to keep their father alive. Witnessing how the technology had impacted their father, the Abbott family became huge advocates for all families impacted by kidney disease and worked tirelessly to focus the attention of Representative Mills on extending this life-saving treatment for all who needed treatment.¹⁰⁵

Because the promise was that most people needing dialysis would be able to work, the bill was signed into law on October 30, 1972 by President Richard M. Nixon and Medicare started to pay for dialysis and kidney transplants on July 1, 1973.¹⁰⁶

¹⁰⁵ American Association of Kidney Patients Annual Meeting 2016 Live Stream. Comment by Bob Abbott on video at 41:31-51:07. <https://aakp.org/livestream/>. Accessed November 30, 2016

¹⁰⁶ Blagg CR. 2007. Ibid

APPENDIX C: Disability Evaluation Under Social Security

Listing of Impairments

<https://www.ssa.gov/disability/professionals/bluebook/>

Adult Listings (Part A): **6.00 Genitourinary Disorders**

A. *Which disorders do we evaluate under these listings?*

We evaluate genitourinary disorders resulting in chronic kidney disease (CKD). Examples of such disorders include chronic glomerulonephritis, hypertensive nephropathy, diabetic nephropathy, chronic obstructive uropathy, and hereditary nephropathies. We also evaluate nephrotic syndrome due to glomerular dysfunction under these listings.

B. *What evidence do we need?*

1. We need evidence that documents the signs, symptoms, and laboratory findings of your CKD. This evidence should include reports of clinical examinations, treatment records, and documentation of your response to treatment. Laboratory findings, such as serum creatinine or serum albumin levels, may document your kidney function. We generally need evidence covering a period of at least 90 days unless we can make a fully favorable determination or decision without it.
2. *Estimated glomerular filtration rate (eGFR)*. The eGFR is an estimate of the filtering capacity of the kidneys that takes into account serum creatinine concentration and other variables, such as your age, gender, and body size. If your medical evidence includes eGFR findings, we will consider them when we evaluate your CKD under 6.05
3. *Kidney or bone biopsy*. If you have had a kidney or bone biopsy, we need a copy of the pathology report. When we cannot get a copy of the pathology report, we will accept a statement from an acceptable medical source verifying that a biopsy was performed and describing the results.

C. *What other factors do we consider when we evaluate your genitourinary disorder?*

1. *Chronic hemodialysis or peritoneal dialysis*.
 - a. Dialysis is a treatment for CKD that uses artificial means to remove toxic metabolic byproducts from the blood. Hemodialysis uses an artificial kidney machine to clean waste products from the blood; peritoneal dialysis uses a dialyzing solution that is introduced into and removed from the abdomen (peritoneal cavity) either continuously or intermittently. Under 6.03, your ongoing dialysis must have lasted or be expected to last for a continuous period of at least 12 months. To satisfy the requirements in 6.03, we will accept a report from an acceptable medical source that describes your CKD and your current dialysis, and indicates that your dialysis will be ongoing.
 - b. If you are undergoing chronic hemodialysis or peritoneal dialysis, your CKD may meet our definition of disability before you started dialysis. We will determine the onset of your disability based on the facts in your case record.

2. *Kidney transplant.*
 - a. If you receive a kidney transplant, we will consider you to be disabled under 6.04 for 1 year from the date of transplant. After that, we will evaluate your residual impairment(s) by considering your post-transplant function, any rejection episodes you have had, complications in other body systems, and any adverse effects related to ongoing treatment.
 - b. If you received a kidney transplant, your CKD may meet our definition of disability before you received the transplant. We will determine the onset of your disability based on the facts in your case record.
3. *Renal osteodystrophy.* This condition is the bone degeneration resulting from chronic kidney disease-mineral and bone disorder (CKD-MBD). CKD-MBD occurs when the kidneys are unable to maintain the necessary levels of minerals, hormones, and vitamins required for bone structure and function. Under 6.05B1, “severe bone pain” means frequent or intractable (resistant to treatment) bone pain that interferes with physical activity or mental functioning.
4. *Peripheral neuropathy.* This disorder results when the kidneys do not adequately filter toxic substances from the blood. These toxins can adversely affect nerve tissue. The resulting neuropathy may affect peripheral motor or sensory nerves, or both, causing pain, numbness, tingling, and muscle weakness in various parts of the body. Under 6.05B2, the peripheral neuropathy must be a severe impairment. (See §§ 404.1520(c), 404.1521, 416.920(c), and 416.921 of this chapter.) It must also have lasted or be expected to last for a continuous period of at least 12 months.
5. *Fluid overload syndrome.* This condition occurs when excess sodium and water retention in the body due to CKD results in vascular congestion. Under 6.05B3, we need a description of a physical examination that documents signs and symptoms of vascular congestion, such as congestive heart failure, pleural effusion (excess fluid in the chest), ascites (excess fluid in the abdomen), hypertension, fatigue, shortness of breath, or peripheral edema.
6. *Anasarca (generalized massive edema or swelling).* Under 6.05B3 and 6.06B, we need a description of the extent of edema, including pretibial (in front of the tibia), periorbital (around the eyes), or presacral (in front of the sacrum) edema. We also need a description of any ascites, pleural effusion, or pericardial effusion.
7. *Anorexia (diminished appetite) with weight loss.* Anorexia is a frequent sign of CKD and can result in weight loss. We will use body mass index (BMI) to determine the severity of your weight loss under 6.05B4. (BMI is the ratio of your measured weight to the square of your measured height.) The formula for calculating BMI is in section 5.00G.z
8. *Complications of CKD.* The hospitalizations in 6.09 may be for different complications of CKD. Examples of complications from CKD that may result in hospitalization include stroke, congestive heart failure, hypertensive crisis, or acute kidney failure requiring a short course of hemodialysis. If the CKD complication occurs during a hospitalization that was initially for a co-occurring condition, we will evaluate it under our rules for determining medical equivalence. (See §§404.1526 and 416.926 of this chapter.) We will

evaluate co-occurring conditions, including those that result in hospitalizations, under the listings for the affected body system or under our rules for medical equivalence.

D. How do we evaluate disorders that do not meet one of the genitourinary listings?

1. The listed disorders are only examples of common genitourinary disorders that we consider severe enough to prevent you from doing any gainful activity. If your impairment(s) does not meet the criteria of any of these listings, we must also consider whether you have an impairment(s) that satisfies the criteria of a listing in another body system.
2. If you have a severe medically determinable impairment(s) that does not meet a listing, we will determine whether your impairment(s) medically equals a listing. (See §§404.1526 and 416.926 of this chapter.) Genitourinary disorders may be associated with disorders in other body systems, and we consider the combined effects of multiple impairments when we determine whether they medically equal a listing. If your impairment(s) does not meet or medically equal the criteria of a listing, you may or may not have the residual functional capacity to engage in substantial gainful activity. We proceed to the fourth and, if necessary, the fifth steps of the sequential evaluation process in §§404.1520 and 416.920 of this chapter. We use the rules in §§404.1594 and 416.994 of this chapter, as appropriate, when we decide whether you continue to be disabled.

6.01 Category of Impairments, Genitourinary Disorders

6.03 Chronic kidney disease, with chronic hemodialysis or peritoneal dialysis (see 6.00C1).

6.04 Chronic kidney disease, with kidney transplant. Consider under a disability for 1 year following the transplant; thereafter, evaluate the residual impairment (see 6.00C2).

6.05 Chronic kidney disease, with impairment of kidney function, with A and B:

A. Reduced glomerular filtration evidenced by one of the following laboratory findings documented on at least two occasions at least 90 days apart during a consecutive 12-month period:

1. Serum creatinine of 4 mg/dL or greater; or
2. Creatinine clearance of 20 ml/min. or less; or
3. Estimated glomerular filtration rate (eGFR) of 20 ml/min/1.73m² or less.

AND

B. One of the following:

1. Renal osteodystrophy (see 6.00C3) with severe bone pain and imaging studies documenting bone abnormalities, such as osteitis fibrosa, osteomalacia, or pathologic fractures; or
2. Peripheral neuropathy (see 6.00C4); or
3. Fluid overload syndrome (see 6.00C5) documented by one of the following:
 - a. Diastolic hypertension greater than or equal to diastolic blood pressure of 110 mm Hg despite at least 90 consecutive days of prescribed therapy, documented

- by at least two measurements of diastolic blood pressure at least 90 days apart during a consecutive 12-month period; or
- b. Signs of vascular congestion or anasarca (see 6.00C6) despite at least 90 consecutive days of prescribed therapy, documented on at least two occasions at least 90 days apart during a consecutive 12-month period; or
4. Anorexia with weight loss (see 6.00C7) determined by body mass index (BMI) of 18.0 or less, calculated on at least two occasions at least 90 days apart during a consecutive 12-month period.

6.06 Nephrotic syndrome, with A and B

A. Laboratory findings as described in 1 or 2, documented on at least two occasions at least 90 days apart during a consecutive 12-month period:

1. Proteinuria of 10.0 g or greater per 24 hours; or
2. Serum albumin of 3.0 g/dL or less, and
 - a. Proteinuria of 3.5 g or greater per 24 hours; or
 - b. Urine total-protein-to-creatinine ratio of 3.5 or greater.

AND

B. Anasarca (see 6.00C6) persisting for at least 90 days despite prescribed treatment.

6.09 Complications of chronic kidney disease (see 6.00C8) requiring at least three hospitalizations within a consecutive 12-month period and occurring at least 30 days apart. Each hospitalization must last at least 48 hours, including hours in a hospital emergency department immediately before the hospitalization.”

APPENDIX D: Social Security Work Incentives

People who have a chronic illness and who fear that their illness may prevent them from keeping their job need to know about the Social Security work incentive programs and how to use them to work with their disability, which could help them keep their Medicare or Medicaid and, in some cases, their cash benefits. For more information and examples of how these programs work, see also Social Security's *The Red Book: A Guide to Work Incentives* for additional information and definitions at <https://www.ssa.gov/redbook/>.

For your convenience, below are sections quoted verbatim from the Social Security detailed patient information document located at <https://www.ssa.gov/disabilityresearch/wi/detailedinfo.htm>

Impairment Related Work Expenses or IRWE (SSI and SSDI)

We deduct the cost of certain impairment-related expenses that you need in order to work from your earnings when we decide if you are performing substantial work. Examples of impairment-related expenses are things such as wheelchairs, certain transportation costs and specialized work-related equipment.

We also exclude IRWE from your earned income when we figure your monthly SSI payment amount.

Subsidies and Special Conditions (SSI and SSDI)

"Subsidies" and "Special Conditions" refer to support you receive on the job that could result in your receiving more pay than the actual value of the services you performed. We deduct the value of subsidies and special conditions from your earnings when we decide whether you are working at the SGA level.

Following are examples of subsidies and special conditions:

- *You receive more supervision than other workers doing the same or a similar job for the same pay.*
- *You have fewer or simpler tasks to complete than other workers who are doing the same job for the same pay.*
- *You have a job coach or mentor who helps you perform some of your work.*

We do not deduct subsidies or special conditions when we figure your SSI payment amount.

Unincurred Business Expense (SSI and SSDI)

"Unincurred business expenses" refers to self-employment business support that someone provides to you at no cost. In deciding whether you are working at the SGA level, we deduct unincurred business expenses from your net earnings from self-employment. Examples of unincurred business expenses are (1) a Vocational rehabilitation agency gives you a computer that is used in a graphic arts business; and (2) a friend works for your business as unpaid help.

For an item or service to qualify as an unincurred business expense:

- *It must be an item or service that the IRS would allow as a legitimate business expense if you had paid for it; and*
- *Someone other than you must have paid for it.*

One way to identify an unincurred business expense is that the Internal Revenue Service (IRS) does not allow you to deduct the cost for income tax purposes because someone gave you the item or services. We do not deduct unincurred business expenses from earnings when we figure your SSI payment amount.

Unsuccessful Work Attempt (SSDI and SSI)

An unsuccessful work attempt is an effort by a disabled individual to do substantial work that either stopped or produced earnings below the Substantial Gainful Activity level after 6 months or less because of:

- *The individual's disabling condition, or*
- *Elimination of the special services or assistance that the individual needed in order to work.*

Unsuccessful work attempts are not factors when we calculate your SSI payment amount.

Continued Payment Under a Vocational Rehabilitation Program (also known as Section 301 Payments) (SSI and SSDI)

If you medically recover and no longer meet SSA's definition of disability, your monthly payments can continue if you are actively participating in an approved VR program that is expected to help you become self-supporting. Your monthly SSDI and/or SSI Payments can continue until you complete the program.

Trial Work Period (SSDI)

The trial work period allows you to test your ability to work for at least 9 months. During your trial work period, you will receive your full disability benefit regardless of how much you earn as long as your work activity has been reported and you continue to have a disabling impairment. The 9 months does not need to be consecutive and your trial work period will last until you accumulate 9 months within a rolling 60-month period. Certain other rules apply.

Extended Period of Eligibility (SSDI)

If your disability benefits stop after successfully completing the trial work period because you worked at the substantial gainful activity (SGA) level, we can automatically reinstate your benefits without a new application for any months in which your earnings drop below the SGA level. This reinstatement period lasts for 36 consecutive months following the end of the trial work period. You must continue to have a disabling impairment in addition to having earnings below the SGA level for that month.

Continuation of Medicare Coverage (SSDI)

Most persons with disabilities who work will continue to receive at least 93 consecutive months of Hospital (Part A); Supplemental Medical Insurance (Part B), if enrolled; and Prescription Drug coverage (Part D), if enrolled, after the 9-month Trial Work Period. You do not pay a premium

for Part A. Although cash benefits may cease due to work, you have the assurance of continued health insurance. (93 months is 7 years and 9 months.)

Author note: Although Medicare coverage typically ends 36 months after transplant, when a transplant recipient has another disability besides ESRD, Medicare continues indefinitely. And, when a transplant recipient continues to work despite having a disability besides ESRD, the “continuation of Medicare” work incentive program will allow him or her to keep Medicare Part A for free and to pay a premium for Part B for 7 years and 9 months after income leads to loss of SSDI cash benefits. SSI and SSDI beneficiaries must report earnings to Social Security to avoid an overpayment.

Medicare for People with Disabilities Who Work (SSDI)

After premium-free Medicare coverage ends due to work, some persons who have returned to work may buy continued Medicare coverage, as long as they remain medically disabled. Some persons with low incomes and limited resources may be eligible for state assistance with these costs under various Medicare Savings Programs. Your state Health and Human Services agency makes the determination about whether you qualify for this help.

Author note: If someone with non-dialysis CKD continues to work with a disability beyond the 93 months that free Medicare is provided, s/he or his or her employer could pay premiums for both Medicare Part A and Part B.

Earned Income Exclusion (SSI)

We do not count the first \$65 of the earnings you receive in a month, plus one-half of the remaining earnings. This means that we count less than one-half of your earnings when we figure your SSI payment amount. We apply this exclusion in addition to the \$20 general income exclusion. The \$20 general income exclusion is first applied to any unearned income that you may receive.

Student Earned Income Exclusion (SSI)

If you are under age 22 and regularly attending school, we do not count up to \$1,780 of earned income per month when we figure your SSI payment amount. The maximum yearly exclusion is \$7,180. These amounts are for the year 2015; they may be adjusted each year based on the cost-of-living.

Blind Work Expenses (SSI)

Earned income that a blind individual uses to meet the expenses of working does not count when we determine SSI eligibility and payment amount. The expenses do not need to be related to blindness and include earned income used to pay income taxes, meals consumed during work hours, transportation costs or guide dog expenses.

Plan to Achieve Self-Support or PASS (SSI)

A plan to achieve self-support allows you to use your income and/or things you own to reach a work goal. For example, you can set aside money to go back to school, or to get specialized training for a job or to start a business. Your goal should be a job that allows you to earn enough to reduce or eliminate your need for benefits provided under the Social Security and Supplemental Security Income programs. We don't count the money or resources you set aside under an approved PASS when we decide your initial or continuing eligibility for SSI. Having a PASS may help you qualify for SSI or may increase the amount of your SSI payment.

Property Essential to Self-Support or PESS (SSI)

We do not count some resources that you need to be self-supporting when we decide if you are eligible for SSI. For example, we don't count property such as tools or equipment that you use for work. Or, if you have a trade or business, we don't count property such as inventory.

Special SSI Payments for People Who Work

You can receive SSI cash payments even when your earned income (gross wages and/or net earnings from self-employment) is at the SGA level. To qualify under this provision, you must have been eligible for an SSI payment in the month before you started working at the SGA level, still be disabled, and meet all other eligibility rules.

Continued Medicaid Eligibility Under Section 1619 (b) (SSI)

Your Medicaid coverage can continue even if your earnings along with your other income become too high for an SSI cash payment. In addition to the qualification requirements for Section 1619(a) below, you must need Medicaid in order to work and meet certain income restrictions.

Special Benefits for People Eligible Under Section 1619 (a) or (b) Who Enter a Medical Treatment Facility (SSI)

Section 1619(a) of the Supplemental Security law permits people to continue to receive an SSI payment while they work. Under Section 1619(b), you may continue to be eligible for Medicaid coverage. If a beneficiary is eligible under section 1619, they can receive a SSI cash benefit for up to 2 months while in a Medicaid facility or a public medical or psychiatric facility.

Reinstating Eligibility Without a New Application (SSI)

If you have not been eligible for an SSI benefit for 12 months or less, you do not have to file a new application to reinstate your SSI cash payments or Medicaid coverage.

APPENDIX E: Federal Employment, Healthcare, and Disability Laws

Affordable Care Act (ACA)

The ACA prohibits insurance companies from denying coverage based on a pre-existing condition, eliminates annual and lifetime benefit limits on “essential services,” allows children to stay on a parent’s plan until age 26, requires insurance to provide certain preventive care benefits for free, closes the Part D coverage gap (doughnut hole) over time, and allows US citizens and permanent legal residents to buy coverage through the state or federally facilitated the Health Insurance Marketplace during an annual enrollment period or other times if they qualify for a special enrollment period. Those with limited income who buy a Marketplace plan may be eligible for help to pay premiums and out-of-pocket costs. Some private insurance companies sell “qualifying health coverage” (coverage that meets the ACA requirements) at times during the year besides the open enrollment period. There is a federal tax penalty for not having “qualifying health coverage” unless an individual meets one of the exceptions. The ACA allowed states to expand Medicaid to cover more of their residents; some states did do so, while others did not.

<https://www.healthcare.gov/>

Age Discrimination in Employment Act

The law forbids discrimination in hiring, firing, pay, job assignments, promotions, layoff, training, fringe benefits, and any other term or condition of employment for people age 40 or older. An employment policy or practice that applies to everyone, regardless of age, can be illegal if it has a negative impact on applicants or employees age 40 or older and is not based on a reasonable factor other than age. The Equal Employment Opportunity Commission enforces this law.

<https://www.eeoc.gov/laws/statutes/adea.cfm>

Civil Rights Act of 1964 (Title VII)

This law makes it illegal to discriminate against someone on the basis of race, color, religion, national origin, or sex. The law also makes it illegal to retaliate against someone who has complained about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit. The law requires employers to reasonably accommodate applicants' and employees' sincerely held religious practices, unless doing so would impose an undue hardship on the operation of the employer's business.

<https://www.eeoc.gov/laws/statutes/titlevii.cfm>

Consolidated Omnibus Budget Reconciliation Act (COBRA)

COBRA allows someone who loses a job while working for an employer of 20+ employees to keep health insurance coverage for 18 months (or 29 months if s/he is deemed disabled). To keep health coverage, the employee must pay up to 102% of the premiums; or potentially even more when the employee is disabled. An employer must continue to offer COBRA to an eligible worker who had Medicare before a loss of employment and COBRA enrollment. However, an

employer can terminate COBRA coverage for employees who enroll in Medicare after a loss of employment. The Department of Labor enforces provisions of COBRA.

<https://www.dol.gov/ebsa/faqs/faq-consumer-cobra.html>

Equal Pay Act of 1963 (EPA)

This law makes it illegal to pay different wages to men and women if they perform equal work in the same workplace, and makes it illegal to retaliate against someone who complains about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit.

<https://www.eeoc.gov/laws/statutes/epa.cfm>

Family and Medical Leave Act (FMLA)

An eligible person who works for a covered employer can take up to 12 weeks of unpaid leave per year for certain reasons, including their own or certain family member's serious illness (26 weeks for an eligible member of military service or certain family members). To be eligible, the employee must have worked for the covered employer for at least 12 months (not necessarily consecutively), worked at least 1,250 hours in the last 12 months, and work in a location where the employer has at least 50 employees within 75 miles. Covered employers include those in the private sector with at least 50 part-time employees in the last year, and public sector employer, public, or private elementary or secondary schools of any size. FMLA protects the person's job (or an equivalent job), pay, benefits, and other terms and conditions of employment. Employers must continue health plan coverage during FMLA, and leave can be taken all at once or intermittently, if possible without undue disruption to the employer's operations. Employees should provide 30 days' notice for foreseeable leave, or otherwise as much notice as possible. Employees may be asked to use sick and vacation time for FMLA.

<https://www.dol.gov/whd/fmla/>

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA protects workers and their families by prohibiting discrimination in group health insurance based on certain "health factors" when certain conditions arise. With HIPAA protection, someone can get new group health insurance coverage without fear of being excluded or denied due to a health condition if they need new coverage because of marriage; birth/adoption; loss of eligibility for other coverage because of divorce, separation, death of a spouse, job loss, or reduction in work hours; a plan that stops covering part-time employees; a move out of an HMO's area; or if a dependent ages out of a plan. The employee or dependent must request enrollment within 30 days after losing eligibility for coverage or after a marriage, birth, adoption, or placement for adoption. The employee or dependent must request enrollment within 60 days of the loss of coverage under a state CHIP or Medicaid program or the determination of eligibility for premium assistance under those programs.

https://www.dol.gov/ebsa/faqs/faq_consumer_hipaa.html

Individuals with Disabilities in Education Act of 2004 (IDEA)

This law ensures that states provide early intervention, special education and other services needed by children with disabilities ages birth to 21

<http://idea.ed.gov/explore>

Rehabilitation Act

The Rehabilitation Act prohibits discrimination on the basis of disability in federal employment in programs run by federal agencies, federal contractors', and programs that receive federal financial assistance, using the same discrimination standards as Title I of the ADA. The Act also authorizes vocational rehabilitation formula grant programs including supported employment, independent living, and client assistance. The Rehabilitation Act authorizes Rehabilitation Services Administration-administered training and service discretionary grants as well as research activities administered by the National Institute on Disability and Rehabilitation Research and work of the National Council on Disability.

<https://www.eeoc.gov/laws/statutes/rehab.cfm> and
<https://www.disability.gov/rehabilitation-act-1973/>

Social Security Act and Amendments

Signed in 1935, the Social Security Act set up retirement benefits for workers and dependents, disability benefits for Social Security Disability Insurance and Supplemental Security Income, the Ticket to Work program, unemployment benefits, Temporary Assistance to Needy Families, State Children's Health Insurance Program, Medicare, and Medicaid. To qualify for Medicare or SSDI, someone needs to have enough work credits. *How You Earn Credits*¹⁰⁷ describes how many credits are needed at different ages. Younger people who become disabled don't need as many credits to get SSDI and Medicare as people over age 31. In 2016, it takes work earnings of \$1,260 to get one work credit. To get four credits, the most you can get in a year, someone has to earn is \$5,040. Those who don't have enough work credits to get Medicare can work and earn credits to get Medicare later. The booklet *Medicare*¹⁰⁸ describes who qualifies for Medicare, the four parts of Medicare, and what Medicare does and doesn't cover.

https://www.ssa.gov/OP_Home/ssact/ssact-toc.htm

Social Security Act: Medicaid

This program provides certain mandated healthcare services, medications, treatment-related transportation, dialysis, kidney transplant, etc. to people who are elderly, blind, or disabled, and to children and pregnant women. Certain services have small copays, and states can choose to cover additional optional services. States set their own income guidelines for Medicaid, so eligibility varies across the country, but all who qualify for Medicaid have limited income and assets. In states that expanded Medicaid under the ACA, individuals do not have to

¹⁰⁷ Social Security Administration. How You Earn Credits. <https://www.ssa.gov/pubs/EN-05-10072.pdf>. Accessed September 7, 2016

¹⁰⁸ Social Security Administration. Medicare. <https://www.ssa.gov/pubs/EN-05-10043.pdf>. Accessed September 7, 2016

be disabled to get Medicaid coverage if they meet the income guideline. People with Medicaid can get services from any Medicaid provider.

<https://www.medicaid.gov>

Social Security Act: Medicare

U.S. citizens and legal residents who have been in the U.S. at least five years qualify for Medicare if they are at least 65 years old, have received Social Security Disability Insurance (SSDI) checks for 24 months or have ESRD requiring dialysis or transplant to survive, AND have enough work credits. Spouses or children with ESRD can qualify under a parent's work history. ESRD is the only specific diagnosis that Medicare covers without applying for disability. Since 2001 Medicare covers those with Lou Gehrig Disease starting the month they get disability with no 24-month waiting period.

Medicare has four parts:

- **Part A**, which is free for most people, covers hospital, home health, hospice and skilled nursing. Those who do not have enough work credits can pay a premium to obtain Part A. Deductibles are charged to all, as are copays for hospital stays from 60-150 days. The last 60 of the 150 hospital days are "lifetime reserve days" which, once used, are gone forever. Part A also covers skilled nursing stays from 20-100 days long.
- **Part B** pays for doctors, outpatient services, home health and other services, including dialysis and some medications—including transplant anti-rejection drugs. Part B has a premium, an annual deductible, and generally pays 80% for Medicare covered services.
- **Part C** is Medicare Advantage (MA) coverage through an HMO, PPO, or Private Fee-for-Service plan. MA plans must provide at least the same benefits as traditional Medicare and they can have optional coverage of services traditional Medicare does not cover. MA has different premiums and out-of-pocket costs currently limited to \$6,700/year.
- **Part D**, prescription drug coverage purchased through insurance companies, provides coverage for drugs included in a plan's formulary with a premium and copays or coinsurance. Most people have a gap in their drug coverage after drug costs reach a certain level. For those whose drug costs are very high, there is catastrophic coverage, after which they pay a 5% copay for each drug. Insurance companies set the costs of drugs in "tiers." The least costly drugs are common generics and the most costly drugs are specialty brand name drugs.

People with traditional Medicare often buy a Medigap (Medicare supplement) plan to help pay the 20% Medicare doesn't pay. Medicaid can help pay those costs for people with limited income and assets, including those who have Medicare and qualify for a Medicare Savings Program. People with Medicare Advantage plans cannot have a Medigap plan to help pay out-of-pocket costs. Read more about Medicare in *Medicare & You* at

<https://www.medicare.gov/pubs/pdf/10050.pdf>.

Workforce Innovation and Opportunity Act (WIOA)

WIOA improves access to education and job services for those with significant barriers to employment, including disabilities. WIOA provides state vocational rehabilitation agencies funds to help people with an immediate need for services or equipment to prevent job loss even if the state is under “order of selection,” when a state does not have enough funding for all applicants, so the federal government requires applicants to be prioritized by severity of disability, with the most severely disabled served first.

<https://www.doleta.gov/WIOA/>

APPENDIX F: Employment-Related Data & Resources

CareerOneStop

Sponsored by the U.S. Department of Labor offers multiple services, including the ones below:

CareerOneStop for Workers with Disabilities

This website has information on these topics for people with disabilities

- Defining disability and the ADA
- Gain skills
- Job search
- Interviews
- Disclosing a disability
- Job accommodations
- Vocational Rehabilitation

<http://www.careeronestop.org/ResourcesFor/workerswithdisabilities/workers-with-disabilities.aspx>

CareerOneStop for Youth - Get My Future

This site has pages for these interests:

- Find a career I like
- Finish high school
- Get work experience
- Write a resume
- Get a job
- Get training
- Work for myself
- Apply to college
- Find job search help

<http://www.careeronestop.org/getmyfuture/index.aspx>

CDC National Health Interview Survey 2015

Adults Ages 18 and Older with Self-Reported Kidney Disease¹⁰⁹

Selected Characteristic	Number Told They Have Weak or Failing Kidneys
Total (18 and older)	4,850,000 (100%)
Ages 18-64	2,367,000 (48.9%)
18 and older, includes retired/age:	
Employed (full or part-time)	1,086,000 (22.4%)
Not employed, worked before	3,526,000 (72.7%)
Not employed, never worked	237,000 (4.9%)
Health insurance coverage <65	
Private	1,025,000 (21.1%)
Medicaid	772,000 (15.9%)
Other	345,000 (7.1%)
Uninsured	245,000 (5.1%)

¹⁰⁹ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center on Health Statistics. Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2015, Table A-4b

Employer Tax Credits

Small Business Tax Credit helps businesses with 30 or fewer employees that made less than \$1 million by providing a tax credit of up to \$5,000 annually to cover accessibility expenses.

Work Opportunity Tax Credit helps employers who hire and retain new employees from targeted groups, such as vocational rehabilitation referrals, including (Ticket to Work) Ticket Holders with individual work plans developed by an Employment Networks. The credit is 40% of the first year's wages up to \$6,000 if the person keeps the job for 400 hours (25% if the job is kept 120 hours).

Job Accommodation Network

Accommodation Ideas for Renal/Kidney Disease

The askjan.org site has many resources for people with disabilities. This link is to one specific to people with kidney disease

<http://askjan.org/soar/other/renal.html>

Recruiting, Hiring, Training and Promoting People with Disabilities: A Resource Guide for Employers

- Best Practices for Recruiting Candidates with Disabilities
- Best Practices for Respecting, Retaining and Promoting Employees with Disabilities
- Best Practices for Providing Reasonable Accommodations
- The Legal Framework: The Americans with Disabilities Act of 1990 and Section 503 of the Rehabilitation Act of 1973

https://www.whitehouse.gov/sites/default/files/docs/employing_people_with_disabilities_toolkit_february_3_2015_v2.pdf

Some Resources for Youth with Disabilities

Center for Parent Information and Resources

This site has multiple links to resources for transitioning from youth to adult, including information for:

- General audiences
- Parents
- Professionals
- Students

<http://www.parentcenterhub.org/repository/transition-starters/>

National Collaborative on Workforce and Disability

This site has links to publications and resources, and target audiences, including parents and families, youth, and youth service professionals.

<http://www.ncwd-youth.info/>

Pathway to Employment for Youth with Disabilities Corporation for National & Community Service

In addition to other resources, this site has information on:

- Work-Based Learning Experiences - Why They are Important
- Benefits Associated with Service Learning and Volunteerism
- The Link Between Volunteerism and Competitive Employment
- Income Exclusions for Service Learning Stipends Available to Social Security Beneficiaries Participating in AmeriCorps
- What Is AmeriCorps?
- What Income Exclusions are Available?

<http://www.nationalservice.gov/about/pathway-to-employment>

Physical Activity & Nutrition

Centers for Disease Control & Prevention

Resources for physical activity for different audiences.

<http://www.cdc.gov/physicalactivity/resources/index.htm>

Information about physical activity specifically for people with disabilities:

<http://www.cdc.gov/nccdphp/sgr/disab.htm>

The Patient's Council on Fitness, Sports, and Nutrition

Information on exercise, healthy eating, etc.

<http://www.fitness.gov/>

The U.S. Department of Agriculture

A program that helps you track food, activity, and more.

<https://www.supertracker.usda.gov/>

A database to look up food nutrients (up to 3 at a time).

<https://ndb.nal.usda.gov/ndb/nutrients/index>

The U.S. Surgeon General's Step It Up program provides information about how to get walking.

<http://www.surgeongeneral.gov/library/calls/walking-and-walkable-communities/exec-summary.html>

Life Options has a guide for nephrologists to help prescribe safe exercise for those on dialysis that could be used with those with non-dialysis CKD.

http://lifeoptions.org/catalog/pdfs/booklets/pro_prescguide.pdf

Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease

http://iriforum.org/download/27IRI_kidney_desease.pdf

This training manual for vocational rehabilitation counselors was developed by vocational rehabilitation leaders and counselors, renal professionals and patients with funding from the Rehabilitation Services Administration for the 27th Institute on Rehabilitation Issues. The manual is divided into chapters that follow the vocational rehabilitation process:

- Chapter 1: What is Kidney Disease and Its Treatment?
- Chapter 2: Referral
- Chapter 3: Vocational Service, Planning, and Delivery
- Chapter 4: Job Development, Job Placement, Job Retention
- Chapter 5: Where Can I Go for More Help?
- Directory of Resources for People with Kidney Disease
- Toolkit