



Improving lives THROUGH
supports and services
THAT FOSTER self-determination.

Past, Present and Future Supports for Individuals with Developmental Disabilities

From Eleemosynary to Nanotechnology



INSANE

Moron

idiot

Imbicile

*Educable, Trainable, and Custodial
Crazy*

feeble-minded

Mad

**MENTALLY
RETARDED**



Pre Institutionalization

- 👤 Family
- 👤 Use of jails for custodial care
- 👤 Community
- 👤 Church



Influence of Europe

- 👤 Philippe Pinel and Moral Management
- 👤 Jean-Marc Gaspard Itard and Victor – the Wild Boy of Aveyron
- 👤 Natural Man philosophy



Institutionalization

- 🕒 No distinction between developmental disability and mental illness

“I come to present the strong claims of suffering humanity. I come to place before the Legislature of Massachusetts the condition of the miserable, the desolate, the outcast. I come as the advocate of helpless, forgotten, insane and idiotic men and women ... of beings wretched in our prisons, and more wretched in our Alms-Houses.

I proceed, Gentleman, briefly to call your attention to the state of Insane Persons confined within this Commonwealth, in cages, closets, cellars, stalls, pens: Chained, naked, beaten with rods, and lashed into obedience!” Dorethea Dix



Growth of the Institution

- 👤 Suicide of Governor Reynolds February, 1844
- 👤 Succeeded by Gov. Marmaduke who proposed establishment of an insane asylum
- 👤 Proposal from Judge R.W. Wells who estimated 1280 Missourians who were “insane” or “idiotic” and “fit subjects for an asylum.” (p. 6-7 Evolution of a Missouri Asylum” Richard Lael, Barbara Brazos and Margo Ford McMillen 2007)
- 👤 Bill signed into law Feb 16, 1846



Rapid Expansion of Institutional Care

- 👤 State Hospitals (serving both MI and DD)
- 👤 Fulton (1847), St Louis (1861/1948), St Joseph (1872), Nevada (1885), Farmington (1889)
- 👤 Names: Asylum for the Insane, Lunatic Asylum, State Hospital,



“Treatment” in Institutions

- 👤 Kindness and fresh air (sometimes)
- 👤 Medication
- 👤 Physical cures
- 👤 Physical restraint and isolation
- 👤 Useful work as treatment
 - 👤 Self sufficiency of the institutions
- 👤 Eugenics and the push for sterilization
- 👤 Psychosurgery (last lobotomy 1966)



“Prefrontal lobotomy has recently been having a certain vogue, probably not unconnected with the fact that this makes the custodial care of patients easier. Let me remark in passing that killing them makes custodial care still easier.”

Norbert Weiner, 1948



- 👤 1951 - Highpoint of number of individuals in the state hospitals –
 - 👤 12,317 in five state hospitals,
 - 👤 2400 in two state schools,
 - 👤 Average patient stay was 13 years.
- 👤 1953 - “Dope Fiends” and addicts added to mission of state hospitals





Titles and Attitudes

- 🕒 1921 - “Eleemosynary Board of Managers” established to run State Hospitals and State Sanitarium
- 🕒 1946 – “Department of Public Health and Welfare, Division of Mental Disease”
- 🕒 1969 - Division name changed to “Division of Mental Health”
- 🕒 1973 – Reorganization into “Department of Mental Health”
- 🕒 1974 – “Division of Mental Retardation and Developmental Disabilities” under DMH
- 🕒 2008 – “Division of Developmental Disabilities”



Other Dates of Note

- 🕒 1965 Sheltered workshop legislation enacted (\$2/day)
- 🕒 1966 – Special education programs for the mentally retarded and emotionally disturbed
- 🕒 1969 Senate Bill 40 passed – counties funding services to support workshops and group homes (Pike County was first in 1970)



Separation of Developmental Disability from Mental Illness

- 👤 1910: Henry Goddard's translation of Binet's test of intelligence
- 👤 1935: Vineland Maturity Scale was developed to assess daily living skills and adaptive behavior of individuals suspected of having mental retardation
- 👤 Rise of "Training Schools" for children with developmental disabilities



DD Specific Institutions

- 🕒 Marshall (1889) “Missouri State Colony for Feeble-minded and Epileptic”
 - 🕒 Expanded into three campuses at Marshall, Higginsville, and Carrolton
 - 🕒 Higginsville facility had been a home for Confederate soldiers, Carrolton had been a state orphanage
 - 🕒 1959 name change to “State School and Hospital” Higginsville separated from Marshall 1970
 - 🕒 Eventually habilitation centers in St Louis (2), Nevada, Higginsville, Marshall



State Regional Diagnostic Centers

- 🕒 1964 State buys O'Reilly General Hospital in Springfield and builds first Regional Diagnostic Center
- 🕒 1965 Legislation for nine “Regional Diagnostic Clinics for the mentally retarded”



State Regional Diagnostic Centers

- 1967 – Regional Diagnostic Centers open in Albany, Hannibal, Joplin, Springfield
- 1968 – Regional Diagnostic Centers open in Kirksville, Poplar Bluff, Rolla, Sikeston
- 1970 – KC Regional Diagnostic Center
- 1972 – St Louis Regional Center for Developmentally Disabled (established but not funded till 1973)



St. Louis – Local to State

- 👤 “St. Louis Training School” 1922
- 👤 Transferred to the State 1948 “St. Louis State Training School”
- 👤 1959 name changed to St. Louis State School

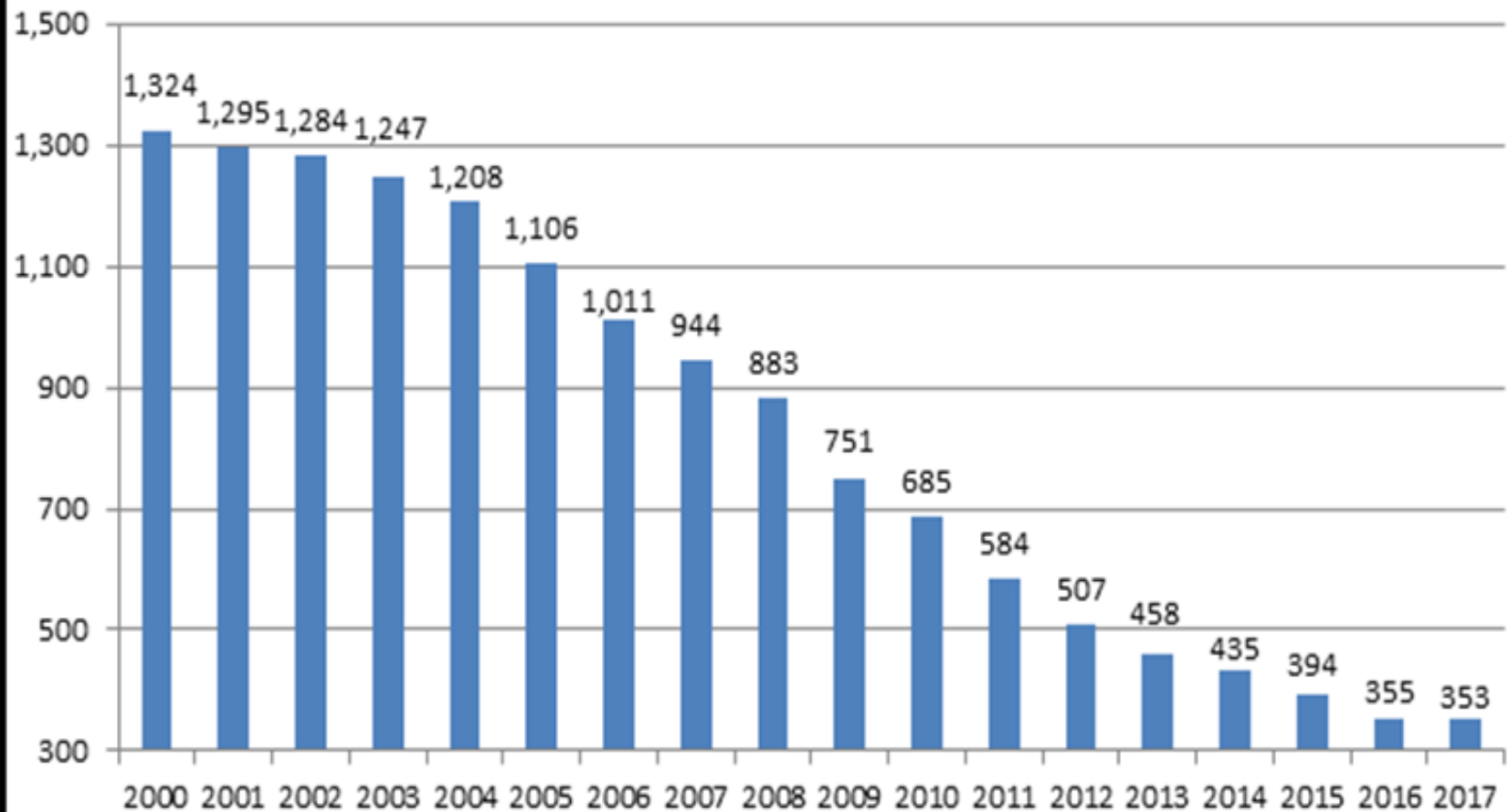


Change in Role of Regional Offices

- 👤 Provided direct services – education, speech, occupational therapy, nursing for children living at the diagnostic centers
- 👤 Provided assessment and case management
- 👤 Changed with Leake decree (federal court case) in 1985
- 👤 Current Regional Offices do not provide formal assessment (IQ, Speech or other therapy evaluations) or educational services.



Habilitation Center: On-Campus Long Term Census For Fiscal Years 2000 to 2017



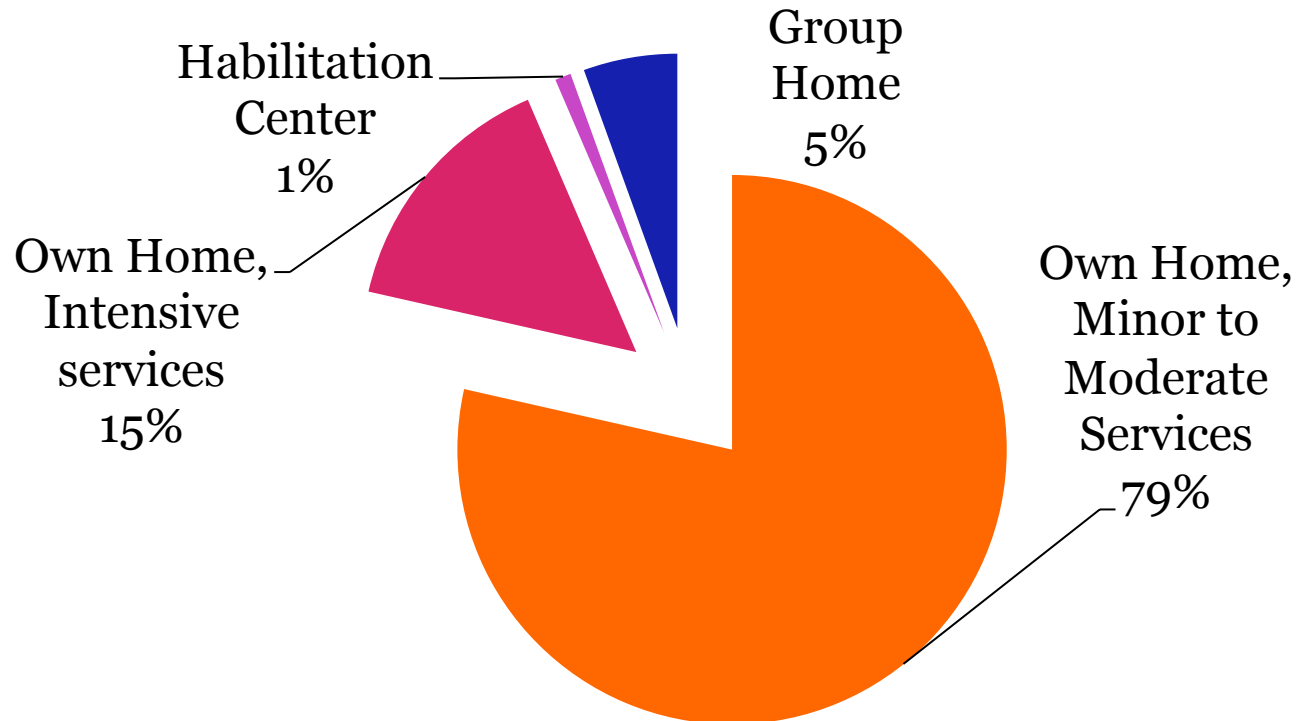


From Institutions to Integration

- 👤 Habilitation Centers – 341 (less than 1% of Division of DD participants)
 - 👤 Intermediate Care facilities for Individuals with Intellectual and Developmental Disabilities – ICF/IDD's
- 👤 Group Homes – 2140
- 👤 Natural Homes with intensive support
 - 👤 97% private, 3% State owned
- 👤 Natural Homes with minor to moderate support



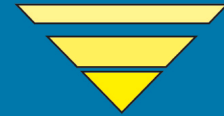
Where do People Live?





Medicaid Waiver Programs

- 👤 Partnership for Hope
- 👤 Missouri Children with Developmental Disabilities (AKA “Lopez”)
- 👤 Community Support Waiver
- 👤 Comprehensive Waiver



Non Division of Developmental Disabilities Services

- 👤 First Steps
- 👤 Early Childhood Special Education
- 👤 Department of Health and Senior Services
 - 👤 Children and Youth with Special Healthcare Needs
- 👤 Special Education
 - 👤 Special School Districts
 - 👤 State Schools
- 👤 Medicaid Program
- 👤 Vocational Rehabilitation
- 👤 Social Security Disability Income



Focus on a Typical Life

- 👤 ADA
- 👤 Olmstead
- 👤 Home and Community Based Waiver Services (HCBS)



Then is Now: Headlines

- 👤 **7 Special Needs Teens Rescued from Locked Room of ‘deplorable’ Texas House (12/17/2016)**
- 👤 **Deputies arrest five after woman with autism found living in backyard cage (7/7/2016)**



Then is Now: Headlines

- 👤 **Tennessee deputies find 10-year-old boy with autism locked in wooden cage (2/7/2017)**
- 👤 **St. Charles County parents of autistic boy kept in cage say on stand that they did their best (4/16/2015)**



Then is Now







Challenges of the Future

- 👤 Demographics of caregivers
- 👤 Education and advancement opportunities
- 👤 Qualified staff and personnel



Demographics

- 🕒 Home health care services and services for people who are elderly or disabled are each expected to grow by over 80 percent.
- 🕒 Direct-care workforce growing 48 percent, an increase of 1.6 million new jobs for home health aides, nursing assistants and personal care assistants.14
- 🕒 84% of personal care aids and 90 % of nursing, psychiatric and home health aids are women
- 🕒 The number of females in the workforce between 25 and 54 is not expected to keep pace.

Bureau of Labor and Statistics, U.S. Department of Labor, Current Population Survey, <http://www.bls.gov/cps>

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Wage Pressure

- 👤 Number of unfilled positions keeps increasing, at 150 or about 1/4 of positions now
- 👤 Competing with other organizations and businesses who are more flexible in their ability to raise wages and costs



The (Perhaps Not so Distant) Future

- 👤 Conception of disability
 - 👤 Dx vs Fx
- 👤 Social Services
- 👤 Medical Advancement



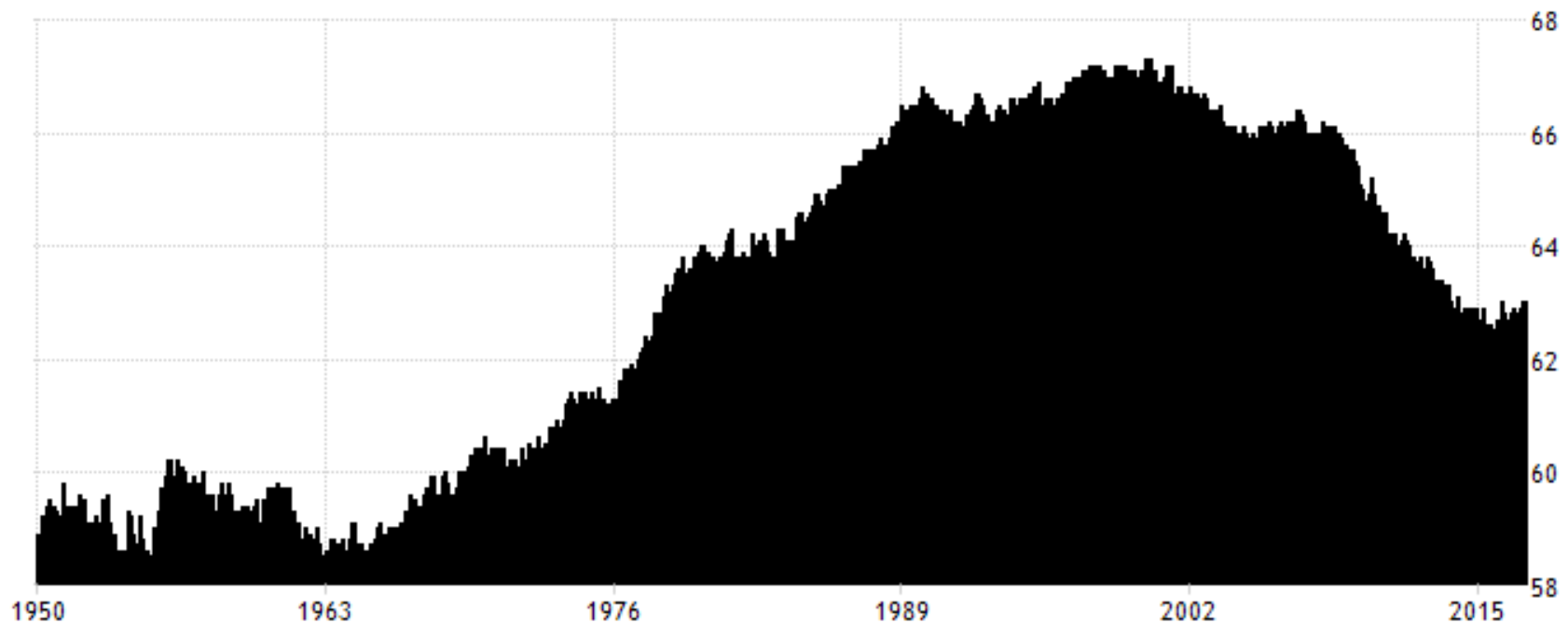
The Changing World of Work

- 👤 Artificial Intelligence and Robotics
 - 👤 Employment implications
 - 👤 Service/Support implications



The World of Work

US LABOR FORCE PARTICIPATION RATE



SOURCE: WWW.TRADINGECONOMICS.COM | U.S. BUREAU OF LABOR STATISTICS



Social Program Changes

Guaranteed Basic Income

- 👁️ ***Debating a Basic Guaranteed Income for All.*** (Wall Street Journal, April 17, 2017)
- 👁️ ***The Pros And Cons Of Basic Income.*** (Nasdaq, April 12, 2017)
- 👁️ ***Artificial intelligence adds to case for guaranteed income.*** (Cambridge Times, April 11, 2017)
- 👁️ ***Why Finland is ahead of the US with guaranteed income.*** (CNBC, January 3, 2017)



Social Program Change Medicaid Block Grants

Conversion of Medicaid (and possibly SSDI) into direct to state grants administered with loose Fed rules

- 👁️ ***Should Medicaid Be Converted to a Block-Grant Program?*** (Wall Street Journal, April 17, 2017)
- 👁️ ***Medicaid block grants give states more freedom.*** (The Hill, March 21, 2017)
- 👁️ ***Strapped States Know Just What to Do with Medicaid Block Grants.*** (Daily Yonder, April 11, 2017)
- 👁️ ***Medicaid Block Grants Would Imperil Disabled Kids.*** (Scranton Times-Tribune, March 26, 2017)

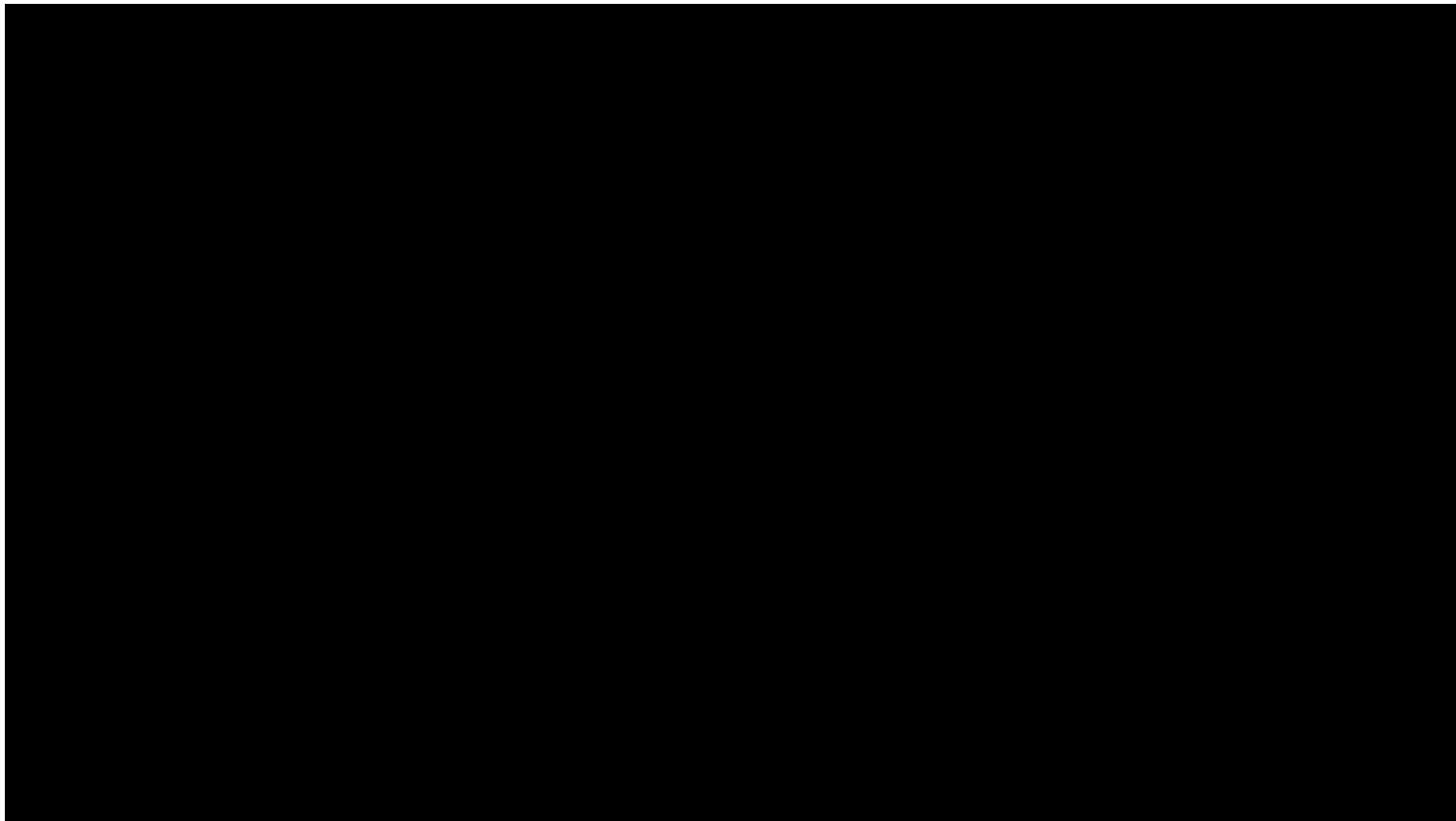


Emerging Technologies

- 🧠 Artificial Intelligence
- 🧠 Nanotechnology

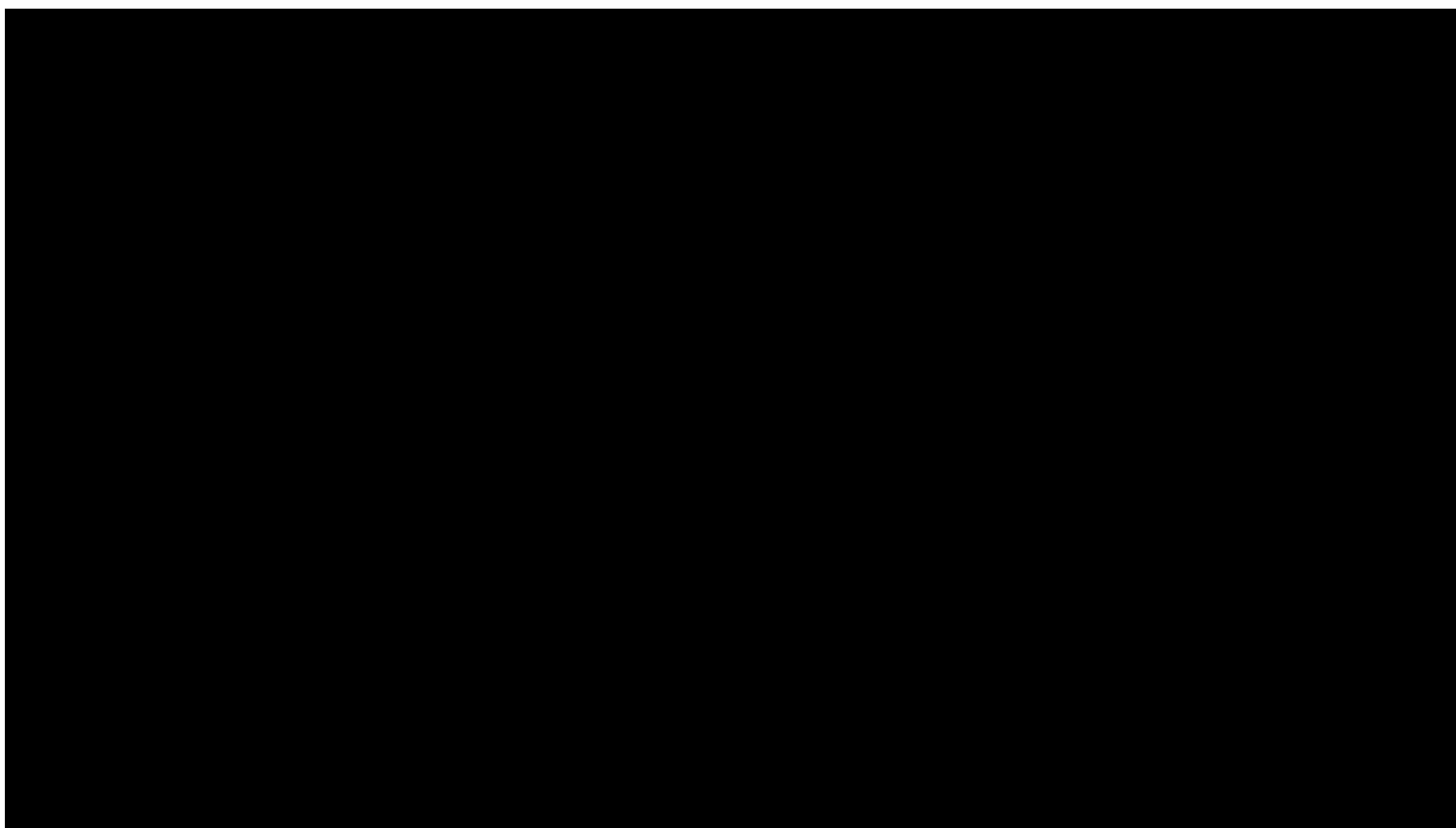


Kevin Kelly (author of “Inevitable”)





Nanotechnology





Sources and Resources

- 📍 Parallels in Time – Minnesota Department of Administration, Council on Developmental Disabilities
- 📍 Kevin Kelly “The Inevitable: Understanding the 12 Technological Forces That Will Shape Our Future”
- 📍 Bureau of Labor Statistics, U.S. Department of Labor, “Employment Outlook 2010-2020,” Monthly Labor Review, Volume 135, Number 1



Sources and Resources

- 📍 Glore Psychiatric Museum, 3406 Frederick Avenue, St. Joseph, MO 64506
- 📖 “Evolution of a Missouri Asylum” Lael, Richard, Brazos, Barbara & Ford, Margo McMillen (2007)
- 📊 Bureau of Labor Statistics, U.S. Department of Labor, “Employment Outlook 2010-2020,” Monthly Labor Review, Volume 135, Number 1, January 2012, Table 2, <http://www.bls.gov/opub/mlr/2012/01/mlr201201.pdf> (accessed 6 April 2012).



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