



North Jersey Health Collaborative

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# Managing Co-Morbid Health Implications for People with Disabilities & Their Caregivers

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The Family Resource Network





# The Family Resource Network

The Family Resource Network (FRN) is dedicated to offering individuals and their families with continuing needs the greatest opportunities, resources and services to support a full and happy life.

The Network was founded as an Epilepsy organization in 1970 after a small interest meeting of families in West Orange, NJ



**The Family  
Resource  
Network**

Providing families with access, answers and action





# Values

- The person shall participate to the fullest extent possible in their own care.
- The family and community are vital resources for the individual.
- Volunteer leadership and participation of people with intellectual and developmental disabilities is essential to the success of the organization.
- Duplication of effort shall be avoided as resources and services are developed for the persons we serve.
- Services and activities shall address the full spectrum of our clients' needs.
- Program activities shall meet defined program standards set by the Department's of Health and Human Services, and other relevant accrediting bodies.



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# Health and Innovation

Guiding the organization to be a leading provider of supports, education and resources that improve the quality of life for individuals with disabilities, chronic conditions, and their caregivers through the development and provision of trainings, care coordination, advocacy and population health management in a culturally competent and innovative approach that increases access to care.





# The Community

- Individuals with intellectual and developmental disabilities
- Increased early mortality compared with the general population
- Diminishing health among primary family caregivers
- People with intellectual disabilities are significantly more likely to have more chronic conditions
- Individuals who reside at home
- Individuals who are eligible to receive in-home and community-based supports



# Addressing Co-Morbidities

## Physical Conditions

- Epilepsy
- Constipation
- Visual impairment
- Parkinson's disease
- Hearing loss
- Dyspepsia
- Psoriasis or eczema
- Thyroid disorder
- Bronchiectasis
- Diabetes
- Migraine
- Asthma
- Pain
- Stroke
- Glaucoma
- Chronic kidney disease
- Heart failure
- IBS
- COPD
- Atrial fibrillation
- Viral hepatitis
- Hypertension
- Cancer
- Arthritis
- Cirrhosis
- Multiple sclerosis
- Diverticular disease
- Peripheral vascular disease
- Chronic sinusitis
- Coronary heart disease

## Mental Health Conditions

- Schizophrenia
- Anxiety disorders (including Agoraphobia and social phobia)
- Dementia
- Depression
- Anorexia or Bulimia
- Alcohol misuse



People with disabilities need coordinated care and services irrespective of where they live, and at a much earlier age than the general population. They require tailored and inclusive initiatives to reduce inequalities.



# Addressing Social Determinants of Health

- Health Related Social Needs
  - The strategic integration of health **equity** in the community before and after the person is a patient, that addresses their social determinants of health
- Population Health Management
  - Addressing the complex health and social needs of high risk/vulnerable populations (value, engagement, access)





## HEALTH OUTCOMES

Mortality, Morbidity, Life Expectancy, Health Care Expenditures,  
Health Status, Functional Limitations

Economic Stability	Neighborhood and Physical Environment	Food	Community and Social Context	Education	Health Care System
Employment	Housing	Hunger	Social Integration	Literacy	Health Coverage
Income	Transportation	Access to Healthy Options	Support Systems	Language	Provider Availability
Expenses	Safety		Community Engagement	Early Childhood Education	Quality of Care
Debt	Parks		Discrimination	Vocational Training	Provider Linguistic and Cultural Competency
Medical Bills	Playground			Higher Education	
Support	Walkability				

Adapted from Kaiser Family Foundation  
<https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>



# Addressing Health-Related Social Needs

- The strategic integration of health **equity** in the community before and after the person is a patient, that addresses their social determinants of health
  - Employment opportunities, non-discriminatory work environments, and equal pay
  - Accessibility to education and educational attainment
  - Accessibility of affordable, nutritious food
  - Housing that is accessible, clean, and safe
  - Accessible community groups and social support
  - Ability to participate in daily life
  - Health literacy



# Population Health Management

- Addressing the complex health and social needs of high risk/vulnerable populations (Value, Engagement, Access)
  - Community Health Workers
  - Care Coordination
  - Home and community-based services
  - Information and Referral
  - Health education
  - Advocacy



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# Programs & Services

For additional information on the full menu of services, please visit [www.familyresourcenetwork.org](http://www.familyresourcenetwork.org)





# Direct Support Services

- Support Services are direct support services provided to the individual with intellectual and developmental disabilities and their family caregivers.
  - In-home and Out-of-home respite care
  - Behavioral Support
    - Intensive In-Home Behavioral Services
    - Individual Support Services
    - Intensive In-Community Counseling Services
  - Camp NOVA
  - After School Programs
  - Recreation Programs
  - Assistive Technology



# Care Coordination and Family Support

- A single, coordinated system of information and access that enhances individual choice and supports informed decision making.
  - Support Coordination
  - Specialized Information & Referral
  - Get Covered NJ – Health Insurance Navigator
  - Employment
    - EDGE (Employment, Development, Guidance & Engagement)
    - NJWINS (Social Security Work Incentives Planning & Assistance – SSI/SSDI)



# Training and Health Education

- An ongoing effort to deliver valuable training and education resources that ensure informed-decision making and the appropriate navigation of the systems of care.
  - Disease/Disability State Education
    - TRUST - Seizure Recognition & First Aid – [www.paulslaw.org](http://www.paulslaw.org)
  - Disability Awareness Programs
  - Disability Sensitivity Training
  - Cultural Awareness and Competencies
  - Individual, Family and Community Supports
  - Coverage to Care
  - Center on Nutrition and Disability
  - Webinar Series – [www.disabilitywebinar.org](http://www.disabilitywebinar.org)



# Advocacy and Community Engagement

- Through continued engagement, FRN has 51 years of established and trusted relationships within the community
  - Caregiver Coalitions
  - Autism Community Impact Board
  - Epilepsy Community Impact Board
  - Get FIT Coalition
  - Family Support Council's





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# COVID-19

*“Inclusion of persons with disabilities in the COVID-19 response and recovery is a vital part of achieving the pledge to leave no one behind.” – UN Secretary General*

Public Health emergencies such as the COVID-19 pandemic do not create inequities, rather they expose the inequities that already exist.



# The Impact of COVID-19: Physical Health (Obesity)

- Children and adults with mobility limitations and intellectual or learning disabilities are at greatest risk for obesity.
- Annual health care costs of obesity that are related to disability are estimated at approximately \$44 billion.
- Obesity is one of the underlying health conditions associated with the most serious consequences of COVID-19 infection, including higher risk of hospitalization and death.
- Since the start of the pandemic, 42 percent of adults in the U.S. experienced weight gain, according to a Harris Poll conducted in February 2021. The average self-reported weight gain amongst U.S. adults was 29 pounds.
- Socioeconomic factors such as poverty and discrimination have contributed to higher rates of obesity among certain populations. Black adults have the highest level of adult obesity nationally at 49.6 percent; Latino adults have an obesity rate of 44.8 percent. The adult obesity rates for whites is 42.2 percent. Asian adults have an obesity rate of 17.4 percent.
- Rates of childhood obesity are also increasing: 19.3 percent of U.S. young people, ages 2 to 19, have obesity. These data more than tripled since the mid-1970s and Black and Latino youth have substantially higher rates of obesity than do their white peers.



# The Impact of COVID-19: Mental Health

- Adults with disabilities report experiencing mental distress 4.6 times more than those without disabilities
- More than half of all adults with both cognitive and mobility disabilities reported mental distress
- Approximately 4 in 10 adults nationwide have reported symptoms of anxiety or depressive disorder during the pandemic—a four-fold increase from pre-pandemic levels.
- Non-Hispanic Black adults (48%) and Hispanic or Latino adults (46%) are more likely to report symptoms of anxiety or depressive disorder than white adults (41%).



# Future of Care for People with Disabilities

- Coordination of care between public health, medical care and human services – Accountable Care Communities and Social Care Networks
- Prioritization of social determinants of health for people with disabilities that addresses intersectionalities
- Application of value-based care within human services
- Whole-person approach to care for people with disabilities using models such as the medical home model placing the individual and their caregiver at the center of the model with shared decision-making



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# Thank you

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