



“The nicest thing you can do when you meet someone with a disability is to **focus on their abilities.**”

-Lois Goodman

## Setting the Stage

Our mission is to magnify and focus the power of community resources to prevent and address our most pressing social needs. Among the key strategic priorities integral to accomplishing our mission is to advance the common good by making a measurable impact in our community. This blueprint represents a new approach for planning how we will invest resources. While it does not fundamentally change our work, it likely will change how we go about that work.

In preparing for this new process, our Community Investment Cabinet worked with staff to develop the following resource investment philosophy.

*Our investment philosophy builds on the foundation of our mission, vision and values and is intended to guide our work in making resource investment decisions that will accomplish meaningful and lasting change in peoples' lives.*

- Our first responsibility is to serve our community.
- Our focus is clear—we identify priorities and implement effective and efficient strategies to achieve measurable results.
- We work for long-term success and seek to address the root causes of social problems.
- We hold ourselves accountable for the prudent investment of community resources.
- We are willing to take calculated risks and move with urgency to address our community's most pressing needs.
- We value transparency and accessibility through honest and full disclosure to donors, agencies and the general community.
- We build constructive relationships based on mutual respect, candor and understanding.
- We value the perspectives, opinions and experiences of the broadest-possible cross section of people to inform our decisions.
- We set high standards for all we do, assess our performance and learn from our mistakes.

It's also important to note that our blueprint helps guide our resource investment decisions. Just what does that mean? There are three major kinds of resources that the United Way can invest in particular areas of focus:

- 1) Give United Way makes a financial commitment to a particular program in support of a strategy focused on a community need.
- 2) Advocate United Way serves as a convener, advocate and champion for issues identified by our blueprint process. This may result in a public policy initiative or simply convening community leaders for dialogue.
- 3) Volunteer United Way serves as a catalyst in identifying volunteer needs to advance a strategy. For example, if more adults are needed to deliver meals to homebound members of our community, we'll issue a "call to action" to the community.

Any combination of these resources may be invested with the intent of making long-term, sustainable change in our community.

We began our work by learning from the community what matters most to them. After conducting surveys engaging more than 1,200 people, and talking with more than 100 human-service professionals, we learned that people are most concerned about these eight issues:

- 1) violence and unsafe neighborhoods
- 2) family violence, child abuse and elder abuse
- 3) poverty/low income
- 4) support for non-professional caregivers
- 5) adequate food, shelter and clothing
- 6) young children prepared for school
- 7) low graduation rates
- 8) safe, affordable housing

### **Starting at the Beginning...**

With such a compelling list of challenges, where do we begin? To understand how best to tackle the issues and to gain insight into the most effective preventive approaches, we turned to a variety of sources. The answer was quite simple and resoundingly endorsed: start at the beginning. We began by focusing on early childhood and published *Blueprint for Change: Early Childhood* in November 2008; investments guided by that blueprint began in August 2009. To build upon our work in early childhood and to ensure a continuum of supportive services for youth, we felt it imperative to concentrate next on school age youth. The *Blueprint for Change: School Age Youth* was published in July 2009. This was followed in September 2009 with the publication of *Blueprint for Change: Aging*, which focuses on older adults and their caregivers, and in January 2010 with *Blueprint for Change: Crisis Services* to concentrate on individuals and families requiring assistance in meeting their basic needs.

As these blueprints were developed it was with a commitment to ensuring inclusiveness of individuals with disabilities and not developing a separate blueprint for them. We were intentional about this approach, in response to advocates' and providers' concerns about the negative impact of "siloes" funding streams that narrowly define disabilities by diagnosis and restrict funding in ways that limit holistic service delivery for individuals with multiple disabilities. Community response to this declared commitment to inclusion was extremely positive. As we progressed through our work, however, we learned that there is no common definition for disability or inclusion and, understandably, that there is no community plan for transitioning our programs and the community toward inclusiveness of individuals with disabilities.

The best approach was clear: take incremental steps that will sustain strategies that address the needs of individuals with disabilities while working with others to develop definitions and strategies for programs and the community in general to become more inclusive. Thus we began our work in developing the disabilities services blueprint for change, knowing that it was a first step in a journey of change. To narrow our universe of disabilities for resource investments, we turned to the Americans with Disabilities Act (ADA), which views a disability as any physical or mental impairment that significantly impacts a person's major life activities.

Our overall commitment continues to be to strategies that focus on prevention and promote long-term sustainable change. This disabilities services blueprint will impact resource decisions for 2010.

## The Blueprint Process

The blueprint process is simply an enhanced planning tool that allows us to be more...

### **Inclusive**

Hundreds of people were engaged in developing this blueprint. As we shared the process, it changed along the way, thanks to invaluable input of everyone from donors to field experts. The names of those who helped bring our blueprint to life are listed in the acknowledgements at the end of this report.

### **Transparent**

The blueprint provides important documentation of our thinking, our approach and how we intend to accomplish our goals.

### **Proactive**

We have devoted resources to identify the most advanced approaches to community problem-solving so that our community invests its limited resources in strategies that will best address its problems.

We researched a continuum of program models, from emerging to evidence-based. Evidence-based programs, as defined by The Children's Agenda, are those "that have been evaluated using randomized control trials, have been replicated in other communities, and that have strong, positive long-term outcomes." Where available and affordable, evidence-based programs are preferred.

When evidence-based programs are not identified, we look to emerging practices. These are practices that show promise and may achieve evidenced-based status.

In short, we plan on investing in programs that have been proven to work wherever we can. Where we can't, we'll devote the resources needed to evaluate emerging practices.

### **Evaluative**

Historically, United Way has tracked program outcomes. The blueprint process truly raises the bar to look at broader impact. Are our strategies working? What progress are we making toward our long-term goal? The blueprint will help us answer such questions.

The blueprint also articulates a formal assessment and evaluation plan that will ensure transparency to our provider partners and others. Program-level evaluation will be particularly important with this blueprint, given the relatively small number of programs that have been rigorously evaluated on similar populations and that meet the standards to qualify them as evidence-based programs.

The importance of program evaluation is underscored in a report by the Center on the Developing Child at Harvard University:

*"No single program approach or mode of service delivery has been shown to be a magic bullet. The key is to select strategies that have documented effectiveness, assure that they are implemented well, and recognize the critical importance of a strong commitment to continuous program improvement."*

### **Collaborative**

We can't address this work alone, nor can we do it by ourselves. We need strong funding, advocacy and volunteer partnerships. The blueprint process has already proven to be an invaluable tool in sharing our intentions and investments with those partners to help them make decisions and create increased synergy of community resources.

### **Culturally Competent**

Cultural competency and sensitivity was a recurring theme voiced by many of those we talked with throughout the blueprint process. We know that in order to make a positive impact, services must be designed to respect and honor the beliefs, attitudes and behaviors of the people being served as well as those providing the services. Ensuring that this happens will be a continuing focus for United Way as the process moves forward.

## **What We Believe about Individuals with Disabilities**

“What we believe” and “what we know” represents a compilation of all that we know, assume and believe about individuals with disabilities.

- Individuals with disabilities want people to see them and presume they are competent.
- Individuals with disabilities are an important resource. They are active contributors and have as much to give to society as they receive from it.
- Individuals with disabilities value individual choice, self-determination and a range of options in services, including the choice to decline services.
- An individual's values and beliefs may influence the perception of a disability and subsequent decisions that are made.
- Individuals with disabilities are capable of making decisions about their own lives. However, as there is risk in making choices, they may benefit from assistance in understanding those choices as well as the possible outcomes.
- Although disability issues impact a select group of people, all people in any given community will directly or indirectly be impacted at some point in their lives with some disability-related issue. Disability ultimately touches all of us.
- Obstacles to a full, inclusive life in the community include barriers such as:
  - Perception or self-perception associated with a disability
  - Lack of knowledge or understanding about the disability
  - Invisibility of a disability
  - Lack of knowledge or understanding about legal rights and helpful resources
  - Physical or attitudinal barriers to community buildings and places
  - Language or communication barriers
  - Inadequate social supports and difficulty developing meaningful relationships
- Systemic barriers to inclusion and independence for individuals with disabilities include:

- Siloed services and funding streams that follow the diagnosis rather than the person
- Narrow eligibility requirements that make it difficult to access service and supports
- Lack of collaboration between systems and providers to support individuals holistically
- Inclusion is characterized by options for membership and belonging, equal opportunity, relationships with like and non-like persons, value and reciprocity.
- There are disparities in employment opportunities for individuals with disabilities. This can be related to:
  - Myth or stigma associated with disability
  - Impaired vocational development<sup>1</sup> of the individual with a disability
  - Lack of or misunderstanding about the impact of wages on public benefits
  - Confusion or lack of understanding about ADA guidelines and incentives
  - Challenges related to accessible transportation
- A civil society supports and celebrates the rich array of human differences by accommodating the myriad ways in which all people function.<sup>1</sup>
- Independence is characterized by controlling one’s own decisions, safely living in the least restrictive environments and contributing to the strength of the community.
- Reliance on informal care partners is becoming more important as the cost of care rises and economic resources are diminished. Families and non-paid supports are integral to the well-being of the care recipient; resources for informal care partners are critical.

We believe that the voices of individuals with disabilities are important. We concur with the “nothing about us without us” mantra that we heard throughout many conversations across the community. People with disabilities and their informal caregivers told us that they want:

- A full and complete life
- Dignified opportunities for community participation
- The same options for housing, jobs and education that are available to persons without disabilities
- The ability to have control over decisions made about their lives
- To ensure no decisions are made about them or their services without them

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<sup>1</sup> Adapted from National Coalition for Disability Rights (Washington, DC)

## What We Know about Individuals with Disabilities

There is no single, universally accepted definition of disability. Nor is there a consensus among experts about how best to incorporate measurements related to disability in surveys and other data-collection mechanisms. Differences in definition and measurement protocols can lead to disparities in reported numbers of people with disabilities and related statistics.<sup>2</sup>

- Data collected by the Census Bureau estimates that 94,432—about one in seven—Monroe County residents aged 5 and older have at least one disability.
  - 6.6 % (44,675) report having one type of disability
  - 7.3% (49,757) report having two or more types of disabilityTypes of disabilities reported:
  - 3% of Monroe County residents aged 5 and older have a **sensory disability** such as blindness, deafness and/or a severe vision or hearing impairment.
  - 8% have a **physical disability** limiting basic activities such as walking, climbing stairs, reaching, lifting or carrying.
  - 6% have a **mental disability** affecting learning, remembering or concentrating.
  - 2% have a **self-care disability** causing difficulty in dressing, bathing or getting around inside the home.
  - 5% of residents aged 16 and older have a **disability making it difficult to go outside** the home to shop or visit the doctor.
  - 7% of residents aged 16 to 64 have a **disability making it difficult to work** at a job or business.<sup>3</sup>
- Disability rates increase with age, and disability types vary by age. In Monroe County,
  - 7% of residents aged 5 to 15 have at least one disability. The most commonly reported disability for 5-to-15-year olds is a mental disability affecting learning, remembering or concentrating.
  - 12% of residents aged 16 to 64 have at least one disability. The most commonly reported disability in this age group is one that makes it difficult to work at a job or business.
  - 34% of residents aged 65 and older have at least one disability. The most commonly reported disability for adults 65 and older is a physical one that limits basic activities.<sup>4</sup>
- Poverty rates for persons with disabilities are higher than for non-disabled persons, and also vary by age. In Monroe County:
  - The overall poverty rate for residents aged 5 and older with disabilities is 24%, more than twice as high as the 11% poverty rate of non-disabled residents.
  - The poverty rate for residents aged 5 to 15 with disabilities is 33%, compared to 18% for non-disabled residents in the same age range.
  - The poverty rate for residents aged 16 to 64 with disabilities is 30%, compared to 10% for non-disabled residents in the same age range.
  - The poverty rate for residents 65 and older with disabilities is 9%, compared to 7% for non-disabled residents in the same age range.<sup>5</sup>
- The employment rate of Monroe County residents with disabilities aged 16 to 64 is 32%, which is less than half the 74% employment rate of non-disabled residents in the same age range.<sup>6</sup>

- The median earnings of Monroe County working residents aged 16 and older with disabilities was \$15,637, about half that of the \$29,686 of non-disabled working residents in the same age range.<sup>7</sup>
- Educational attainment for Monroe County residents aged 25 and older with disabilities is significantly lower than that of non-disabled residents.
  - 26.0% of residents with disabilities had not earned a high school diploma or its equivalent, compared to 8.5% of non-disabled residents.<sup>8</sup>
  - 16.2% of residents with disabilities had earned a bachelor's or advanced degree, compared to 37.3% of non-disabled residents.<sup>9</sup>
- In 2007-2008, 12.0% (almost 16,000) of Monroe County children and youth aged 4 to 21 were classified with disabilities for special-education purposes.
  - The most common disability was a learning disability, affecting 5,475 children. Experts disagree about whether official numbers accurately reflect the “real” prevalence of learning disabilities in the population because there is no consensus on what constitutes a learning disability or objective identification criteria. Some experts argue that official prevalence rates overcount people with learning disabilities, while others argue that learning disabilities are underidentified.
  - 12.6% of New York State residents in the same age range were classified with disabilities.
  - Six school districts in Monroe County had higher rates than the state's: East Rochester (18.8%), Rochester (15.7%), Wheatland-Chili (15.2%), Brockport (13.7%), Gates-Chili (12.9%) and Churchville-Chili (12.8%).<sup>10</sup>
- New York State law requires that the Individualized Education Plans (IEPs) of students aged 15 and older with disabilities include annual goals and transition services that will help them meet their post high school goals. During the 2007–2008 school year, about four out of ten IEPs did not fully meet all state regulatory requirements for transition planning.<sup>11</sup>
- A longitudinal New York State study conducted by SUNY Potsdam researchers tracked post-school outcomes for a sample of students with disabilities compared to those who were not disabled. This study found that 83% of special-education students who graduated from high school in 2001 had successfully transitioned to employment, postsecondary education and/or a day-program alternative within 9 to 14 months of leaving school compared to 96% of similar general education graduates.<sup>12</sup>
- A survey of a sample of New York State students with disabilities who exited high school in 2006–2007 indicated that 92% had achieved positive post-school outcomes (competitive employment, military service, enrollment in post-secondary school or a combination of these outcomes) within one year of leaving school. The survey, also conducted by researchers at SUNY Potsdam, included both students who had graduated from high school as well as those who had dropped out, although the latter group was underrepresented.
  - 75% of the students had worked competitively at some point during the year after exiting high school.
  - 66% of the students reported having been involved in post-secondary school at some point in the year since leaving school. Of these students, about 4 out of 10

- participated in two-year college programs, and about 2 out of 10 in four-year programs.
  - Outcomes varied by type of school exit. Only 3% of students with a Regents diploma, local diploma or GED did not achieve one of the positive post-school outcomes, compared to 16% of the students who graduated with a modified (“IEP”) diploma and 19% of the students who dropped out.<sup>13</sup>
- A national study funded by the U.S. Department of Education designed to understand the experiences of teens and young adults with disabilities found:
  - Youth with disabilities were less likely to enroll in post-secondary education programs, compared to similar-age youth in the general population (45% compared to 53%).
  - Out-of-high-school youth with disabilities were also less likely to be working at the time of interview (57% compared to 66%). The jobs held by youth with disabilities since leaving high school were of shorter duration (on average, 10 months compared to 15 months).<sup>14</sup>
- A national survey conducted in 2003 indicates that about one in five adult Americans (more than 44 million) provides unpaid care to adult friends and relatives. This could include help with activities such as eating, bathing, dressing, housework and shopping.
  - About 1 out of 5 of these unpaid caregivers is a helping adult between the ages of 18 and 49.
    - Mental illness is the primary problem for almost one in four younger care recipients—by far the most common main problem.
    - Another 5% have a cognitive disability, resulting in nearly three in ten care recipients who are in need of care for non-physical reasons.
  - While providing care, about 3 out of 5 caregivers also work or have worked. Of these, about 3 out of 5 report making some adjustments to their work life as a result of their caregiving responsibilities, from being late for work to giving up their jobs entirely.<sup>15</sup>
- A survey of caregivers aged 65 and older who cared for relatives with serious psychiatric disabilities indicated:
  - 18% had completed future care plans for their relative; 44% had not started any planning at all.
  - The most commonly identified barriers to planning included intense anxiety about the future of their relative (63%), their relative’s resistance to making changes (52%) and lack of knowledge about how to plan (50%).<sup>16</sup>
- A national survey of mothers aged 50 and older living with and caring for their adult children with long-term mental illnesses found that :
  - 11% had definite plans for their children’s future residences, while 52% had done little or no planning.
  - 66% reported that financial arrangements, such as trusts or money willed to another relative on the child’s behalf, had been made for their child’s future.
  - 68% of the mothers perceived the need for formal services to assist with residential planning and 73% for formal services to assist with financial planning.<sup>17</sup>
- Nationally, more than three out of four adults with developmental disabilities live with their families. Demographic trends over the past several decades—including increased life

expectancy for people with developmental disabilities and lower fertility rates overall—have resulted in both an extended period of caregiving for adults with developmental disabilities as well as fewer family members available to help with caregiving.

- Current life expectancy for adults with developmental disabilities ranges from the late fifties for those with more severe disabilities or Down syndrome to 71 for adults with mild to moderate disabilities. In 1931, the average life expectancy for males with intellectual disabilities was 15; for females, 22.
  - About 25% of family caregivers of adults with developmental disabilities (more than 700,000) are at least 60 years old. A source of anxiety for aging caregivers is the future security of their relative when they are no longer able to provide care. Information, service system and other barriers prevent more than half of families from making concrete future care plans.<sup>18</sup>
- The average Medicaid expenditure in New York State per older adult and adult with physical disabilities receiving services in a nursing home was \$32,134, substantially higher than the \$19,551 average cost for those receiving home- and community based-services.<sup>19</sup>
  - Lift Line is the business unit of the Rochester-Genesee Regional Transportation Authority that provides paratransit services in accordance with the Americans with Disabilities Act.
    - In 2008, Lift Line provided 179,280 trips, up 0.6% over 2007.
    - The average fare for a Lift Line trip was \$2.27 in 1999. In 2008, it was \$2.29.<sup>20</sup>
  - Mental health problems can have a major impact on an individual’s quality of life and functioning. The Centers for Disease Control and Prevention uses the “Frequent Mental Distress” (FMD) measure to estimate the prevalence of mental health issues in a community. Individuals are considered to have FMD when they self-report that their mental health was not good during 14 or more of the past 30 days.
    - In 2006, 8% of Monroe County adults reported they had FMD.
    - Adults aged 18–64 (9%) were more than twice as likely to report FMD than adults aged 65 and older (4%).
    - Rochester residents (11%) were almost twice as likely to report FMD than suburban residents (6%).<sup>21</sup>
  - The National Comorbidity Survey Replication was conducted to determine the prevalence of mental disorders among American adults. Intensive diagnostic interviews were conducted with a representative sample of more than 9,000 English-speaking adults. The study determined:
    - Half of mental illness disorders begin by age 14; three-quarters by age 24.
    - The median age of onset for anxiety and impulse-control disorders is 11.
    - The median age of onset for substance-use disorders (including alcohol dependence) is 20.
    - The median age of onset for mood disorders (such as major depressive disorders and bipolar disorder) is 30.
    - The study also found that about half of all Americans will meet the criteria for a mental health disorder at some time in their lives. The authors noted that disorders can vary widely in severity and need for treatment, and that not everyone who meets diagnosis criteria will require treatment.<sup>22</sup>

## Goal and Objectives for Individuals with Disabilities

**Goal:** Individuals with disabilities maximizing independence as fully engaged members of the community.

This goal responds directly to what we heard throughout the community from individuals with disabilities, advocates and caregivers: that inclusion within a community where there are real choices for housing, employment, recreation—all the aspects of life—is vitally important. Individuals with disabilities told us they want to make meaningful contributions to society, yet at times they don't feel valued for their attributes. And although they are capable of making choices about their lives, they said at times they don't feel empowered to do so. Although we do not have specific data, families and professionals who support individuals with disabilities testify to the increase in social isolation and loneliness that unfolds for individuals with disabilities. Many individuals are often not incorporated into the social mix as fluidly, while others are socially disregarded or left behind. These sentiments are echoed across the country.

We've learned that individuals with disabilities commonly call for these four fundamentals:

- 1) accessible places to live
- 2) dignified opportunities to learn, work and contribute
- 3) safe and affordable options for mobility
- 4) meaningful relationships

In order for adults with disabilities to maximize independence and access options to fully participate in society, they must have their basic needs met and they must have:

- physical and attitudinal barriers to inclusion removed
- access to all of the community's many services and supports
- assistance in planning for and making key transitions in their lives

Individuals with disabilities and caregivers agree that our community offers a wide array of services and supports. The keys are: getting information to individuals with disabilities and their caregivers about available services so they can take advantage of them; ensuring transportation is available to get to services and to become involved in the community; and providing person-centered services that can be accessed during key points in a person's life and which are focused on the individual's needs. Simply put, services need to fit the individual. Individuals should not be fit into a program.

*"I definitely think access to services increases community membership and connections within the community. If you have the services that you need, you can be productive and contribute to your community. You are a member of a community that has embraced acceptance and allows you to become a person first in a community. To me, it's a win-win situation for everyone." —Teena Fitzroy, Rochester resident<sup>23</sup>*

While some physical and attitudinal barriers still exist, the Americans with Disabilities Act has expanded opportunities for individuals with disabilities by reducing barriers, changing perceptions and increasing full participation in community life. In this twentieth-anniversary year of the ADA, we are joining advocates and individuals with disabilities across the country in reaffirming our commitment to work toward full accessibility and inclusion of people with disabilities.

We are committed to inclusiveness in the broadest sense and have demonstrated that commitment through our intentional efforts to include the needs of individuals with disabilities into the early childhood, school age youth, aging and crisis blueprints. The early childhood blueprint, for example, focused on the importance of early identification, screening, assessment and services for young children with disabilities. The school age youth blueprint announced the launch of an inclusion-focused learning circle to provide education and peer support for program staff to ensure that youth with disabilities are effectively and appropriately integrated into after-school, mentoring and early-intervention programs. It is important that all services are provided to the diverse people in our community requiring assistance and that every service is offered in a culturally competent and appropriate manner.

Community response to our commitment to inclusion has been extremely positive. Also very well received was our acknowledgement that this commitment is the beginning of a journey—a transition to inclusion—that we will be undertaking as part of a community effort. Creating inclusive blueprints is an early step. Ensuring that strategies within the *Blueprint for Change: Disabilities* are inclusive is another. In response to concerns about the negative impact of siloed funding, which restricts services by diagnosis of disability, we will implement strategies that reach across disability type and are open to, and inclusive of, people whose physical or mental impairment significantly impacts their major life activities. It is important to note that the disability field is undergoing a shift in philosophy and practice to reduce reliance on medical models and move towards a more person-centered, customized and rights-based framework. As a result, a number of emerging practices have not yet undergone rigorous research, thus achieving evidence-based status. Even so these practices have generated significant positive outcomes through implementation.

With this as our backdrop, we have established the following outcomes and indicators:

### **Increased or Maintained Independence**

- Improved self-determination
- Improved competencies of individuals and their nonprofessional caregivers to manage independently, including decision-making, advocacy and service-navigation skills
- Improved social support networks of people with disabilities and their nonprofessional caregivers
- Completion of life-determination plans for and with individuals with disabilities
- Increased utilization by people with disabilities and their nonprofessional caregivers of government entitlements and services necessary to increase independence and quality of life, such as:
  - physical and mental health care
  - service coordination or case management
  - day treatment and rehabilitative services
  - vocational services
  - home care and residential services
  - respite

## Increased Mobility

- Increased utilization of suitable transportation options by individuals with disabilities
- Increased participation in work, volunteer, recreational, social and other activities in the community

## Strategies for United Way’s Resource Investments

### Strategy 1: Transportation

*“My family and friends are an important part of my life. They help me with tough issues, like right now, transportation. I need to figure out transportation or I’ll lose my job. I did what I could, but now I need help from others. We will make a plan and we will make it happen. I feel happy knowing my friends will help me with this if they can.”*

*Joe Santacesaria, Rochester resident<sup>24</sup>*

While our community has several transportation programs focused on the needs of individuals with disabilities, transportation is consistently identified in community needs assessments as lacking. Individuals with disabilities, as well as caregivers and service providers, have expressed frustration with missed opportunities for employment and community participation because of safety issues, limitations in service or the complexity of public transportation systems. Eligibility restrictions, cost and difficulties scheduling trips at specific times are often cited as challenges. The National Organization on Disability reports that “accessible transportation is often a powerful positive predictor not only of employment, but also of several other important quality of life indicators such as political participation, access to entertainment, socializing and religious attendance. Likewise, inaccessible transportation limits the ability of people with disabilities to participate in these activities.”

United Way will make resource investments in transportation programs that serve a broad cross-section of individuals with diverse disabilities, providing them with safe, appropriate and affordable options that promote their independence. These services will include:

- **Travel Training** to assist individuals to identify and use public transit systems, which are recognized as the most cost-efficient means of transportation.
- **Door-to-Door Transportation** (ride services) because public transit is not available in all areas and is not suitable for all passengers. In some cases, specialized service is required to transport individuals with disabilities for non-emergency medical appointments as well as shopping, banking and other essential tasks.
- **Driver Retraining** to assist individuals with disabilities who have been licensed drivers or were able to drive, but whose acquired injury or disability puts them at risk of not being allowed to drive. This service gives individuals who have been affected by a disability the tools to legally possess a NYS driver’s license and independently operate a motor vehicle.

## Strategy 2: Transition Coaching

In general, transition coaching focuses on the process that people go through as they undergo life-shifts. It seeks to provide them with support, a sounding board, encouragement, goal development, assistance in developing natural networks, connections to services and planning.

Transitions are not easy for anyone. They can be particularly difficult for individuals with disabilities and their caregivers, who can find themselves inadequately informed about available services or ineligible for programs because of stringent participation requirements.

In our community we have a wide array of services for individuals with disabilities and their caregivers. Connections to and among those services are essential for an individual with disabilities to maintain quality of life, especially through a transition.

Transition coaching has been effective in supporting older adults and individuals with disabilities in the first four weeks after a hospitalization to reduce re-hospitalization. It has great potential as a tool for coaching people through other life transitions as well. In this application, transition coaching provides short-term assistance—up to six months—to individuals with disabilities and their caregivers who are either not eligible for or not currently enrolled in a care system such as those provided by Office of Mental Retardation and Developmental Disabilities (OMRDD) or the Office of Mental Health (OMH).

Transition coaching is appropriate to assist individuals with disabilities and their caregivers during, or in preparation for, key transitions in life. Among these transitions are the first detection or onset of a disability; an upsurge or flare-up of a disabling condition, such as progression of multiple sclerosis, resulting in decreased mobility; or a movement between care settings, such as from a caregiver home to independent living. A coach guides an individual or caregiver through examining circumstance, exploring current and future options, goal-setting and planning, connecting to resources and evaluating plan outcomes. By coaching rather than leading, this practice is designed to increase the capacity of an individual or caregiver to self-manage a plan through immediate and future situations.

The implementation of transition coaching will be based upon several pillars:

1. **Self-management of disability.** In contrast to traditional case-management approaches, transition coaching is a self-management model in which the individual or caregiver takes the lead in decision-making. The model advances accountability by empowering an individual or caregiver to make informed choices and assume responsibility for those choices. Additionally, this method increases the ability of an individual to prevent or manage future events more independently. This approach often engages a network of individuals to help achieve the designed outcomes of a transition plan. The network may include paid professionals, medical workers, family members or friends and others, who would all play specific roles. The individual with the disability or the caregiver drives the team and plan design, and the transition coach assists by facilitating the process, mentoring and coaching.
2. **Person-center planning approach.** This process-oriented approach empowers individuals with disabilities by acknowledging and supporting their responsibility for and ability to

make decisions about their lives. The transition coach's role is to help the individual set goals and plan for the best way to achieve them.

3. **Connection to specialized care and timely follow-up.** Coaching helps an individual select and connect to community resources for longer-term support including eligibility screening for public benefits and eligibility screening for and connection to services through established systems like those provided by OMRDD and OMH.
4. **Short term in duration.** Transition coaching is available to individuals and their caregivers "as needed" during periods of life transition. The transition coach may provide intensive support for up to six months for each life transition or event requiring support. Some individuals will call on transition coaching just once, while others may require further support as they reach other transition points. For example, an individual may first engage for support and guidance when diagnosed with a disabling condition, and may re-engage when the condition progresses to a point where it impedes the ability to work without accommodation. The individual may again re-engage when transitioning from living with a caregiver to independent living or long-term care housing.
5. **Relationship-building assistance.** Any transition coaching effort must include resources to support individuals in building or rebuilding relationships and social connectedness. Activities can include, for example, information distribution, role-play, utilization of peer supports or bridge-building.

United Way will make resource investments in transition coaching programs that meet a specific set of quality practices and program elements:

- Adoption of a person-centered approach to service
- Ability to deliver services in varied locations, including an individual's home, as appropriate
- Staff who are:
  - highly knowledgeable about community resources
  - skilled in linking individuals to specialized resource assistance, such as Disability Program Navigators or Community Work Incentive Coordinators, who assist in navigating public health benefits—housing, health care, transportation, etc.—that impact employment or employability of individuals with disabilities.
  - clear on the role of a coach in supporting an individual
- Demonstrated capacity and a plan for outreach to unserved/underserved populations
- Focused on growing the individual's or caregiver's natural support network
- Connection to NY Connects, a key resource for all New Yorkers exploring long-term care planning, which is designed to provide connection to transportation, home-delivered meals, counseling, residential options, respite, home care and more.
- Willingness to participate in monthly meetings with other funded partner programs

In our community, the transition coach strategy has been embraced by numerous service providers who work with individuals with disabilities and their caregivers. These providers currently offer coaching services, in a casual way and without funding, to individuals not currently in a system of care. Implementing the transition coach strategy will establish a framework for service delivery across agencies. We expect implementation to be carried out in close partnership between United Way and the providers selected for resource investments in support of transition coaching. Together we will build knowledge about what works best locally, the characteristics of individuals who take advantage of transition coaching, and where gaps in services exist. This will give us a greater understanding of individuals with disabilities and help to inform future services.

### **Strategy 3: Systems Improvement**

Improving the quality and accessibility of services for adults with disabilities and their families is as critical as implementing effective programs. This is especially true in the current environment of increasingly complex needs and decreasing resources to address them. United Way is committed to planning, implementing and sustaining high-quality systems that connect and improve local services. We envision a three-pronged approach to achieve this.

**Learning Circles** involve staff from United Way-funded programs. They will meet regularly to increase coordination among their agencies and share information about emerging programs to reduce duplication of effort and to increase overall provider knowledge for the benefit of clients. During the investment cycle we will launch a learning circle focused on transition coaching. Implementing this strategy will require cooperation among all the agencies involved to assure the best possible services for individuals with disabilities and their caregivers. We will be intentional about creating opportunities to expand learning circles to include individuals with disabilities, caregivers, providers and others working toward the goal of adults maximizing independence and inclusion in the community.

**Knowledge Management** is a practice of harnessing intellectual capital through a practice of identifying, documenting and sharing information. During 2009, United Way launched an internal knowledge management system designed to systematically capture information gained from meetings with experts, presentations, literature reviews and provider reports. This will serve as the foundation for a larger knowledge management system in which funded agencies will participate. Participation includes the ability to add to the system's resources as well as retrieve information and post comments. This approach is intended to increase overall institutional memory and learning among the community of funded service providers. In the long term, we envision that the information harnessed through knowledge management will be made available to any interested party in our community.

**United Way's Synergy Fund** provides technical assistance to agencies interested in exploring a different relationship in order to increase their capacity to pursue their mission. United Way has entered into a partnership with the New York Council of Non-Profits (NYCON), an Albany-based organization with extensive experience in organizational re-engineering, to provide technical assistance to local agencies interested in exploring this opportunity. The process begins with assessing each agency's goals, reviewing their missions and gauging their organizational cultural compatibility. Also provided are facilitation and preliminary due diligence necessary for the boards of both agencies to decide whether to enter into a good-faith agreement to negotiate a different kind of relationship, as are the accounting and legal services required to bring about an envisioned re-engineering that will achieve affiliation, consolidation or merger.

## Integrated Strategies for Our Work

We recognize that we will not fully achieve the goal and outcomes set forth for individuals with disabilities through investments alone. United Way is committed to leveraging other resources as well—chiefly our leadership role in advocacy and volunteerism. We expect that by integrating our investment, advocacy and volunteer strategies we will achieve the declared goals of our blueprints. This integration is new and will take our best and most thoughtful organizational efforts to succeed. As we progress to implementing the blueprints, we will develop clearly articulated plans.

### Integrated Strategy 1: Advocacy

United Way engages in advocacy because we know that real and sustained change in community conditions requires more than money. Our advocacy efforts include public policy work as well as identifying opportunities to convene stakeholders to address local systemic issues.

These efforts, at the local, state and national levels, are often conducted in partnership with United Ways across the state and the country, magnifying our influence to further the goals of our strategies for individuals with disabilities. We'll continue efforts to develop an advocacy agenda to include:

**Advocacy to ensure the inclusion of individuals with disabilities in all aspects of community life.** Efforts to moderate misperceptions about the competence of individuals with disabilities need to be fortified so that our community can fully experience the value of an inclusive society. We are committed to ensuring that as we move forward, we will actively engage individuals with disabilities in our work and encourage other community organizations and leaders to seek out and engage these voices in community-building initiatives.

*“... Everyone has something to offer in this world... I, myself, have Tourette syndrome and I know that if I am able to be included in the community and be more active in this world and with my life, I am able to feel more confident, understand this world and contribute much more than I ever thought. I believe that including everyone into every area of life is very important, not just for people with disabilities, but for those without.”—Matt Giordano, Rochester resident<sup>25</sup>*

**Advocacy in support of statewide efforts to coordinate service systems and transform current models of service across disciplines.** With nearly 50,000 Monroe County residents reporting two or more disabilities, it is imperative that our community be able to provide high-quality care and service suited to a variety of individual needs. United Way will explore statewide efforts to create high-quality systems of care in the most integrated settings possible in order to learn how we might advance efforts for individuals with disabilities.

### **Advocacy for continued funding of 2-1-1 centers to ensure increased access to information and referral**

For the people in our community needing help every day—from locating financial assistance during a family crisis, to finding services for someone with a disability, to searching for the highest-quality child care—2-1-1 is an easy-to-remember number to connect quickly with essential community resources.

At the federal level, United Way of Greater Rochester, in partnership with United Way of America and United Ways across the country, continues to work to secure passage of the Calling for 2-1-1 Act. This act would authorize funding needed to fully implement 2-1-1 nationwide. The legislation has been introduced for several years now, but never successfully moved out of committee. Continued advocacy efforts at the federal level are required. Our local 2-1-1 service is projecting a significant and unsustainable deficit this year. The future of this important resource is at risk and continued advocacy at the state level for state funding is necessary.

## **Integrated Strategy 2: Volunteerism**

The gift of time is perhaps one of the most powerful ways to “give.” As part of our blueprint process, we will continue to work with providers to identify key volunteer opportunities that will help them advance their work. As we identify opportunities, United Way is committed to actively working to spotlight them and recruit volunteers from the community. Some key volunteer opportunities identified by providers include:

- Volunteer drivers who provide invaluable transportation services, particularly in areas that are not well-served with public transportation and among consumers with limited financial means
- Volunteer mentors to provide companionship, engage in activities and forge relationships with adults with disabilities

We acknowledge the abilities and desires of individuals with disabilities to serve as volunteers. We will work with community partners to help them actively recruit individuals with disabilities for volunteer positions and to identify opportunities for them to volunteer.

We will track and evaluate our ability to mobilize volunteers in support of our work.

## **Assessing the Strategies**

We are committed to an outcomes evaluation that will assess the effectiveness of individual funded programs, overall strategies and the blueprint itself. Evaluations will be designed to identify challenges and clarify accomplishments. All evaluations will focus on program outcomes. They will also include measures of process and implementation to maximize our understanding of the relationships between service delivery and results.

For programs that do not rely on evidence-based models, we will require the design of program-specific data-collection tools. Each of these programs will also have a specific evaluation design, data collection and analysis plan. We will work with all providers and evaluators to ensure that data-collection tools are valid and appropriate.

We will report the results of all program evaluations on schedules developed for the individual evaluation design. Funded programs will be required to regularly submit specific outcome data (as specified in their evaluation design) and/or participate in evaluations commissioned by United Way.

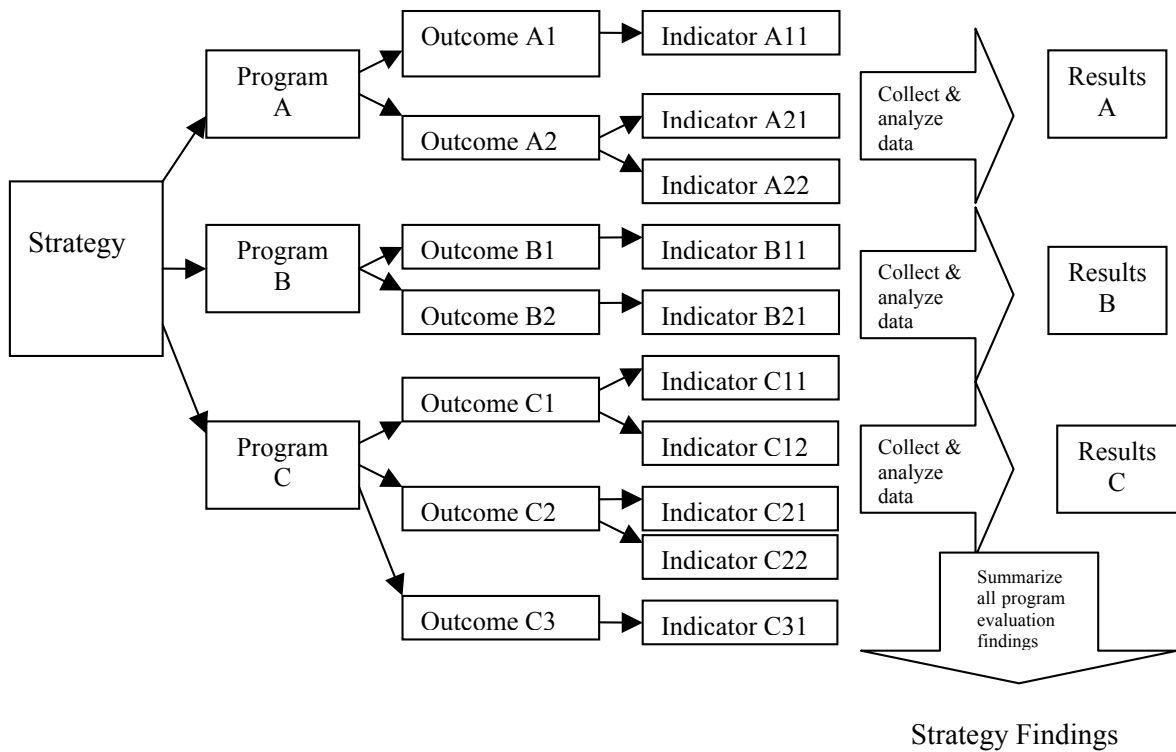
We have commissioned an outside evaluator to assist in this multi-dimensional evaluation process. In addition to program evaluations, there will be strategy evaluations informed by the results of

multiple program evaluations. We will also seek to understand the outcomes of the overall blueprint. To accomplish this we intend to assess the results of all strategy evaluations.

In many program evaluations, we will require evaluators to collect specific feedback from key stakeholders. Additionally, we may commission strategy-level collections of feedback by surveying stakeholders about the effectiveness of the strategy. We also may require that other administrative data be collected and analyzed to further understand strategy outcomes.

We plan to share with the broader community key lessons from the results of our strategy and blueprint evaluations so that our results can influence and inform other efforts.

The following diagram illustrates a strategy-level evaluation that looks to the programs funded at the outcome and indicator level, and seeks to find commonalities across the indicators where possible to aggregate results. The strategy evaluation will also select from funded programs and require the use of a common data-collection and analysis tool called COMET. Use of this tool will enable sharing client-level data with an outside evaluator, who will conduct an analysis and provide feedback on the impact of the overall strategy. It will also have multiple benefits to the program staff who collect and track participant attendance and performance.



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### Disability and Inclusion Advisory Council

*Our Advisory Council works with staff to identify, prioritize, focus and support initiatives and programs. They provide insight that informs strategic investment of resources and advocacy as well as expertise that guides effective investment decisions.*

Dan Meyers	Al Sigl Community of Agencies
Jim Mroczek, LMSW	Arc of Monroe (retired)
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Tiffiney Taylor, MSW	Golisano Children's Hospital
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### Peer Review Panel

*The role of the Peer Review Panel was to offer feedback and counsel on the final draft of the blueprint.*

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Monroe 1 BOCES  
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ABVI Goodwill  
Parent to Parent NYS (The Advocacy Center)  
Volunteers of America  
NYS Dept. of Health: Health and Disability  
Monroe County Office of Mental Health  
School of the Holy Childhood  
Monroe County Resident  
Regional Center for Independent Living  
Catholic Family Center  
NAMI Rochester  
East House  
Mental Health Association  
Mental Health Association  
*formerly of Monroe 1 BOCES*

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## GLOSSARY

**Advisory Council:** A group of United Way volunteers who work within a focus area with United Way staff to identify, prioritize, focus and support initiatives and programs. They provide insight that informs strategic investment of resources and advocacy as well as expertise that guides effective investment decisions.

**Advocacy:** The act increasing public awareness of a particular issue or set of issues, actively supporting a cause and deliberately influencing those who make policy decisions.

**Best Practices:** Processes, practices or systems widely recognized as improving the performance and efficiency of organizations in a target area such as aging services.

**Blueprint for Change:** A planning tool that will inform United Way's investment strategies as well as its advocacy and volunteer efforts. The Blueprint for Change is based on the Theory of Change. (See Theory of Change.)

**Caregiving:** Caregiving may include accessing, arranging and coordinating hands-on personal care; emotional and financial support; managing medical care and other care; transportation; shopping; cleaning; and decision-making about health, financial, personal and legal matters. This care may be full-time or part-time, and may be shared among family caregivers.

**Care Receivers:** Care receivers are individuals with adult-onset long-term disability or illness who need ongoing or intermittent assistance with everyday tasks in order to function. They may or may not live with the family caregiver. They may receive all or part of their care from family caregivers, or they may receive care from others.

**Care Transitions:** Movements between settings that occur as an individual's needs change during the course of a chronic or acute illness or due to changes in the abilities of family caregivers to provide necessary support.

**Coaching:** In early childhood family models, coaching is an evidence-based, interactive process used to provide support and encouragement, refine existing practices, develop new skills and promote continuous self-assessment and learning.<sup>26</sup> In adulthood, coaching is not evidence-based and is simply referred to as a learning strategy that promotes the learner's ability to reflect on his or her actions as a means to determine the effectiveness of an action or practice, and to develop a plan for refinement and use of the action in immediate and future situations (Rush and Shelden, 2005).<sup>27</sup>

**Community:** An interacting group of people living in the same territory—town, village, suburb or neighborhood.

**Cultural Appropriateness:** Relates to sensitivity to the differences among ethnic, racial and/or linguistic groups, and awareness of how people's cultural background, beliefs, traditions, socio-economic status, history and other factors affect their needs and their response to services.

**Cultural Competence:** The knowledge and sensitivity necessary to tailor interventions and services to reflect the norms and culture of a target population and avoid styles of behavior and communication that are inappropriate, marginalizing or offensive to that population. Because of the

changing nature of people and cultures, cultural competency is seen as a continual and evolving process of adaptation and refinement.

**Disability:** Any physical or mental impairment that substantially limits one’s major life activities and is likely to continue indefinitely (lifelong or for an extended duration).

**Emerging Practices:** Practices that appear likely to ultimately be effective, but which have yet to be evaluated at the same level of rigor as evidence-based practices.

**Evidence-Based Practices and Programs:** Approaches supported by scientific evidence showing that a practice is effective in increasing positive outcomes, such as increasing mobility, or reducing negative ones like elder abuse. Although there is no universal standard to define the quality or quantity of research necessary to conclude a practice is “evidence-based,” experts use the following factors to determine the weight of evidence supporting the effectiveness of a program or practice. The type of study used to evaluate the program. Well-executed randomized control trials are generally considered to be the strongest evidence. This design involves randomly assigning participants to receive intervention. Differences between those getting intervention and those serving as the control group are due to the intervention. The next level involves quasi-experimental designs. Here, results for the intervention group are weighed against those of a group that matched as closely as possible on relevant demographic and other characteristics, but did not receive treatment. However, one cannot rule out that differences in outcomes between the two groups are due to unmatched-for characteristics, rather than the intervention itself.

- 1) The sample size of the study. Larger sizes are generally better, as they are more likely to detect significant effects.
- 2) The degree of participant attrition during the study. High attrition may indicate problems with program implementation and can compromise the integrity of the original randomization or matching process, and thus erode confidence in the results.
- 3) The quality and integrity of the measurement tools and procedures used to measure outcomes.
- 4) The strength of the outcomes observed.
- 5) Whether the positive effects of the intervention are sustained after it has ended compared to the control or comparison group.
- 6) Whether the study has been independently examined by a peer review panel and accepted for publication.
- 7) Replication of positive results across more than one site and/or more than one study.

**Family Caregiver:** A non-professional who provides unpaid care for relatives and loved ones in the home. The care recipient might be a member of the caregiver’s family of origin, or family of choice—a special friend, neighbor, support group member or life partner.

**Fidelity:** Fidelity of implementation occurs when implementers of a research-based program or intervention, such as teachers, clinicians or counselors, closely follow or adhere to the protocols and techniques that are defined as part of the intervention. It could also mean correctly sequencing multiple program components, and conducting assessments and evaluations using the recommended or provided tools.

**Goals:** Broad outcomes expected for the community, which, unlike objectives, are not directly measurable.

**Inclusion:** A relationship that exists between two parties when members of the first are also members of the second. Inclusion implies the existence of a reciprocal relationship that embraces mutual dependence, action or influence.

**Independence:** The capacity to make choices and exercise control over one's daily life.

**Individualized Education Plan (IEP):** a legally binding document that identifies the unique needs of a student with disabilities. It sets forth the recommendations for the supports, services, programs and accommodations necessary to address those unique needs and to support that student's participation and progress in the general curriculum.

**Interdependence:** A term that implies an interconnection between two entities, and which suggests a partnership that seeks to maximize potential for both.

**Indicators:** Quantifiable measures of program performance that signify progress (or lack of it) toward a result.

**Informal Caregiving:** A catch-all phrase that refers to unpaid care and financial support provided by family or friends of people with chronic illness or disabilities.

**Integration:** The process of bringing diverse groups together in the same system.

**Intervention:** Anything meant to change the course of events for someone—such as a treatment, medicine, surgery, information or education program or counseling.

**Knowledge Management:** Strategies and processes designed to identify, capture, structure, value, leverage and share an organization's intellectual assets to enhance its performance and competitiveness. It is based on two critical activities: capture and documentation of individual explicit and tacit knowledge; and disseminating that knowledge within the organization.

**Life Determination Plan:** A comprehensive written document that accommodates the future needs of an individual with a disability, including contingencies should the nonprofessional caregiver no longer be able to provide the same level of current support. The plan includes financial, legal, health care and living arrangements, as well as vocational, recreational and other community supports.

**Livable Community:** A livable community is one that has affordable and appropriate housing, supportive community features and services and adequate mobility options, which together facilitate personal independence and the engagement of residents in civic and social life.

**Objectives:** Specific, measurable aims for a strategy that have matching outcomes by which to measure them.

**Outcomes:** A change in behavior, physiology, attitudes, or knowledge that can be quantified using standardized scales or assessment tools.

**Peer Review Panel:** A group of locally and nationally recognized experts, all within the field of disability services, who offered feedback and counsel on the final draft of the Disability Blueprint.

**Public Policy:** Any foundation or public-charity activity intended to affect governmental actions. Activities may include building coalitions, community organizing, convening stakeholders, funding demonstration projects, issue advocacy, leadership development, litigation, media and communications, policy research and analysis, public education and voter registration

**Respite:** A short period of rest or relief. This may be an afternoon, a day, or even a week off from caregiving responsibilities, typically provided on a regular basis by an informal caregiver, home health-care aide or community-based provider.

**Screening:** An abbreviated evaluation performed to detect the need for or likely benefit of a specific service or resource.

**Secondary Conditions:** Conditions to which people with disabilities are more susceptible. Secondary conditions can include diseases, non-medical events such as social isolation and other problems that are more likely to occur because of a primary disability. Studies suggest that environmental factors, health policies and personal attitudes and behaviors can affect risk for secondary conditions. These factors can be targeted through strategies such as:

- Improved availability and accessibility of transportation and medical offices, fitness centers and other facilities
- Use of adaptive equipment and technology
- Policies that facilitate post-secondary education and employment
- Promoting healthy habits and preventive health care

**Social Isolation:** The lack of contact and interaction with other people; the feeling of loneliness or lack of companionship or close and genuine communication with others<sup>28 29</sup>

**Strategy:** An approach chosen to bring about a desired future, such as achieving a goal or solving a problem. Also, the art and science of planning and marshaling resources for their most efficient and effective use.

**Target Population:** The specific group of people or the beneficiaries of a grant project. The individuals in the target population share common characteristics.

**Theory of Change:** By mapping a process from beginning to end, a theory of change establishes a blueprint for the work ahead and anticipates its likely effects. In addition to revealing what should be evaluated, a theory of change also reveals when and how the evaluation should be conducted.

**What We Know and Believe:** “What we know” represents what the data tells us about our community and the people with disabilities who live here. “What we know and believe” represents a compilation of all that we know, assume and believe about individuals with disabilities.

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<sup>1</sup> the long-term impact of having been excluded from age appropriate=opportunities for vocational assessment, work experience and skill training

<sup>2</sup> Cornell University, Employment and Disability Institute, Disabilities Statistics: Frequently Asked Questions. <http://www.ilr.cornell.edu/edi/DisabilityStatistics/faq.cfm?n=7>.

<sup>3</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>. See <http://www.census.gov/acs/www/Downloads/SQuest05.pdf> for the survey questions used to define the different disabilities categories.

<sup>4</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>. See <http://www.census.gov/acs/www/Downloads/SQuest05.pdf> for the survey questions used to define the different disabilities categories.

<sup>5</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>. All poverty rates calculated from the relevant population for whom poverty status is known. Poverty data excludes individuals living in nursing homes and certain other institutional group quarters; see <http://www.census.gov/hhes/www/poverty/povdef.html> for more details.

<sup>6</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>. Applies to the civilian noninstitutionalized population. The Census Bureau counts as “employed” civilians 16 years old and over who were either (1) “at work”—those who did any work at all during the reference week as paid employees, worked in their own business or profession, worked on their own farm, or worked 15 hours or more as unpaid workers on a family farm or in a family business; or (2) were “with a job but not at work”—those who did not work during the reference week but had jobs or businesses from which they were temporarily absent. Excluded from the employed are people whose sole activity consisted of work around the house or unpaid volunteer work. Also excluded are people on active duty in the United States Armed Forces. The reference week is the calendar week preceding the date on which the respondents completed their questionnaires or were interviewed.

<sup>7</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>. Applies to the civilian noninstitutionalized population that reported earnings. “Earnings” is defined for census purposes as the wage or salary income and net income from self-employment, and represents the amount of income received regularly before deductions for personal income taxes, Social Security, bond purchases, union dues, Medicare deductions, etc.

<sup>8</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>. Applies to the civilian noninstitutionalized population.

<sup>9</sup> Calculated from 2005–2007 American Community Survey data obtained from <http://factfinder.census.gov/>.

<sup>10</sup>Local statistics and state statistics obtained and calculated from New York State Education Department Special Education School District Data Profiles available at <http://eservices.nysed.gov/sepubrep/mainervlet?f=county0708&county0708=26>. The district rate is the count of children aged 4 to 21 in the district classified as having disabilities, which includes all school-age students for whom the district has Committee of Special Education responsibility to ensure the provision of special-education services, divided by the total district population of the same age range, including public and nonpublic students.

Information relating to dispute over identification of and prevalence of learning disabilities obtained from Lyon, G. R. “Learning Disabilities”. (1996) *The Future of Children*, 6 (1), pp. 54–76 and a special issue of *Learning Disabilities Quarterly*, 21 (4), devoted to politics and learning disabilities, published in fall 1998

<sup>11</sup>New York State Department of Education. Vocational and Education Services for Individuals with Disabilities. February 2009. Annual Performance Report for 2007–2008. <http://www.vesid.nysed.gov/specialed/spp/apr2009/final.pdf>.

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A monitoring review of 3,225 IEPs from a representative sample of 106 New York State school districts indicated that 59% were in compliance with all state regulatory requirements for transition planning.

<sup>12</sup> New York State Department of Education. Vocational and Educational Services for Individuals with Disabilities. Part B State Performance Plan (SPP) for 2005–2010, Indicator 14. <http://www.vesid.nysed.gov/specialed/spp/plan/postschool.htm>. 13,000 randomly selected special-education and general-education students who graduated from high school in 2000 (beta sample) and in 2001 (main sample) were included in the study.

<sup>13</sup> New York State Department of Education. Vocational and Education Services for Individuals with Disabilities. February 2009. Annual Performance Report for 2007–2008. <http://www.vesid.nysed.gov/specialed/spp/apr2009/final.pdf>. 2,453 students with IEPs were interviewed. Compared to the total population of students with IEPs who exited school in 2006–2007, dropouts were underrepresented by 16.3 percentage points, students with emotional disabilities were underrepresented by 4.0 percentage points, and minorities by 11.5 percentage points.

<sup>14</sup> U. S. Department of Education. “The Post-High School Outcomes of Youth with Disabilities up to Four Years After High School” A Report from the National Longitudinal Transition Study-2”. April 2009. [http://www.nlts2.org/reports/2009\\_04/nlts2\\_report\\_2009\\_04\\_complete.pdf](http://www.nlts2.org/reports/2009_04/nlts2_report_2009_04_complete.pdf).

<sup>15</sup> National Alliance for Caregiving and AARP. “Caregiving in the U.S.” April 2004. <http://www.caregiving.org/data/04finalreport.pdf>. A national telephone survey of 6,139 adults was conducted, from which 1,247 caregivers were identified. “Caregiver” was defined as an adult 18 or older who provided help to one or more adults 18 and older with at least one activity of daily living (such as getting in or out of beds or chairs, getting dressed, toileting, bathing, showering and eating) or an instrumental activity of daily living (such as managing finances, shopping or housework.)

<sup>16</sup> Hatfield, A. B. (2000). “Helping Elderly Caregivers Plan for the Future Care of a Relative with Mental Illness.” *Psychiatric Rehabilitation Journal*, 24 (2), pp. 103–107. A mail-in survey was circulated in Florida and Maryland National Alliance of Mentally Ill newsletters; 210 responses were obtained. As participants were not randomly recruited, the results may not be representative of the total population of older caretakers caring for a mentally ill relative.

<sup>17</sup> Smith, G. C., Hatfield, A. B., & Miller, D. A. (2000). “Planning by Older Mothers for the Future Care of Offspring with Serious Mental Illness.” *Psychiatric Services*, 51(9), pp. 1162–1165. The 157 study participants from 41 states were recruited through advertisements in National Alliance of the Mentally Ill newsletters between 1995 and 1997. As participants were not randomly recruited, the results may not be representative of the total population of mothers 50 and older living with and caring for a mentally ill child.

<sup>18</sup> Heller, T. et al. (2007). “Aging Family Caregivers: Policies and Practices.” *Mental Retardation and Developmental Disabilities Research Reviews*, 13 (2), pp. 136–142.

<sup>19</sup> AARP. “Across the States: Profiles of Long-Term Care and Independent Living.” 2009 (8<sup>th</sup> Edition). [http://assets.aarp.org/rgcenter/il/d19105\\_2008\\_atl.pdf](http://assets.aarp.org/rgcenter/il/d19105_2008_atl.pdf).

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<sup>21</sup> Monroe County Department of Public Health et al. “Monroe County Adult Health Survey Report 2006.” September 2007. <http://www.monroecounty.gov/File/Health/2006%20ADULT%20HEALTH%20SURVEY.pdf> and Health Action. “Adult and Older Adult Health Report Card.” September 2008. <http://www.monroecounty.gov/File/Health/september%2017%20version.pdf>.

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<sup>24</sup> Martha Mock, Ph.D. & Kristen Love, M.Ed. University of Rochester. *Report to the United Way of Greater Rochester: Created to Inform the Disability Blueprint*; pg.31 (Dec. 2009)

<sup>25</sup> Martha Mock, Ph.D. & Kristen Love, M.Ed. University of Rochester. *Report to the United Way of Greater Rochester: Created to Inform the Disability Blueprint*; pg.51 (Dec. 2009)

<sup>26</sup> Joyce and Showers (1982); Kohler, McCullough and Buchan (1995); Morgan, Gustafson, Hudson and Salzberg (1992); Munro and Elliott (1987); Rush, Shelden and Hanft (2003); Showers (1985); Sparks (1986); Tschantz and Vail (2000).

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