# Building an Autism Friendly Community in McLean County

a whitepaper inspired by the AFC campaign

Compiled December 12, 2016



### Welcome me

Expanding awareness, informed service, social supports, and civic engagement opportunities for people with autism

### Learn with me

Creating educational opportunities for people with autism

### Home and transit for me

Ensuring appropriate housing and transportation for people with autism

### Wellness for me

Ensuring healthcare and wellness opportunities for people with autism

### Work with me

Employing people with autism

### Play with me

Creating recreation and leisure opportunities for people with autism



www.autismfriendly.community



The Autism Friendly Community is a collaborative campaign of <u>Autism McLean</u> and <u>Marcfirst</u>, publicly initiated in April "Autism Awareness Month" 2016.

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### **Background and Disclaimer**

This whitepaper was inspired by the Autism Friendly Community (AFC) campaign, initiated by Autism McLean and Marcfirst. The AFC goal is to motivate individuals, businesses, services, local government, and organizations to be welcoming, supportive and inclusive of people with autism and their families.

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Information in this White Paper is accurate to the best of our knowledge. Given the scope of the content and complexity of issues — as well as the lack or inaccessibility of data in some areas — this document is best understood as a general guide to the relevant issues and local situation. It is not an all-inclusive compilation.

**Supplemental information**, including many of the sources used in writing the document, is available in the Appendix.

## **Whitepaper Overview**

**Whitepaper Purpose Statement:** To provide insight into the current status and needs of people with autism, towards the goal of making McLean County an autism-friendly community.

### What is autism?

# Autism Spectrum Disorder is a lifelong neurodevelopmental condition with a broad range of characteristics:

- Language difficulties, ranging from nonverbal to hyper-verbal
- Difficulty navigating social interactions
- Atypical or "eccentric" behaviors
- Perseveration hyper-focus on singular subjects
- Hyper- and hypo-sensitivity to sensory stimuli
- · Difficulty multi-tasking

A specific individual may not have all of the characteristics listed above, but everyone on the Autism Spectrum has problems with social communication.

While people with Autism Spectrum Disorders (ASD) face a wide range of challenges, they also have their own strengths, personality and potential. Addressing needs requires an understanding of autism *and* consideration of each individual's unique characteristics.

# This paper describes relevant needs and opportunities within six quality-of-life categories.

Within each category, the white paper outlines the spectrum of needs for people with autism, the current local situation, and opportunities to address unmet needs in McLean County. The six quality of life categories are:

- Welcome me community awareness, inclusion, social supports and civic engagement
- Learn with me Education and lifelong learning
- Home & transit for me Housing, home life, and transportation
- Wellness for me Healthcare and wellness
- Work with me Employment and workplace
- Play with me Recreation and leisure



### **INTRODUCTION: Why create an Autism Friendly Community?**

This whitepaper advocates for support and understanding of adults and children on the autism spectrum, in order to bring about a higher level of engagement, acceptance, appropriate accommodations and an improved quality of life. This advocacy is based on (1) the numbers of people affected by autism in McLean County, (2) the challenges these citizens face, and (3) the benefits of effectively addressing those challenges.

#### **Prevalence of Autism**

Autism is more common than many familiar childhood conditions, including deafness, childhood cancer, and muscular dystrophy. With 1 in 68 young people meeting criteria for autism (per 2016 CDC estimates), and approximately 170,000 people in McLean County, we can estimate that there are 2500 people with autism in McLean County. If we include the parents, siblings, teachers, employers, and service providers of these individuals, the number of people directly affected by autism in McLean County is substantial.

### **Challenges and Aspirations**

**Autism doesn't end with childhood. It lasts a lifetime.** People with Autism Spectrum Disorder (ASD) face many challenges throughout their life span. In some cases, the challenges and impairments are severe, in others' they may not be immediately obvious. Despite these challenges, people with ASD have many strengths and, given a supportive environment, can flourish and make significant contributions to society.

Improved community understanding of autism is critical to improving outcomes for children and adults with ASD. Self-advocacy — or the meaningful involvement of individuals with autism in making policy at all levels — is also essential to this process. An Autism Friendly Community will support self-advocacy, as well as advocacy by family members and other autism allies. By listening to input from those living with autism, the community can advance public policy initiatives that will provide needed improvements in the quality of life and full access to society for people on the spectrum.

The whitepaper contributors aspire to create an Autism Friendly Community in which both citizens with autism and the community as a whole benefit from empowering individuals with autism to participate fully in society. Full participation means making one's own decisions and being a self-sufficient citizen to the best of one's ability — enjoying the same rights, privileges and responsibility of every other citizen. Unfortunately, barriers to full participation often arise not from physical or mental differences, but from societal attitudes that stigmatize certain types of people as less worthy of inclusion than others.

An Autism Friendly Community will promote respect and acceptance of differences while providing meaningful, inclusive choices with respect to supports, services, friends, allies, and living circumstances.

### An Autism Friendly Community means enhancing:

- Self-determination and independence
- Access to supports, services and therapies
- Access to transportation and community spaces
- Respect and friendship
- Educational and employment choices
- Housing choices in inclusive neighborhoods
- Digital inclusion access to phone, internet, computer, and assistive technology devices

### An Autism Friendly Community means eliminating:

- Invisibility
- Voicelessness
- Bias, bullying, and victimization
- Denial of choices
- Lack of supports
- Lack of control
- Poverty and other financial restrictions

### Welcome me.

### Autism Awareness and Inclusion for People with Autism in McLean County

Purpose Statement: For individuals with autism to fully participate in society, the community must understand autism and foster an environment where people with autism are welcomed as self-advocates and co-creators within the community. This paper will outline the spectrum of needs related to awareness and inclusion, the current local situation, and opportunities to address needs in McLean County.



### **A Spectrum of Needs**

An autism friendly community, at its core, welcomes those with autism. Because autism affects the way an individual communicates, behaves, and thinks about the world, welcoming communities make efforts to understand and accommodate those differences.

Creating a welcoming inclusive community begins with autism awareness and training. Two major barriers to acceptance of people with autism include (1) social stigma and (b) insufficient knowledge. Autism training can reduce these barriers and increase community responsiveness. Informational and training needs include:

- Information about resources for people with autism and their families (e.g., support groups, autism-friendly services, businesses and activities)
- General information about autism for all community members
- Training for local businesses, organizations and agencies to help them better welcome, engage, serve and respond to people with autism
- Advanced autism training for organizations that directly serve people with autism
- Support (financial, staff, space, materials) for carrying out these autism awareness activities

Creating a welcoming autism-friendly community also means opening up opportunities for inclusion, civic engagement, and self-advocacy for people with autism. This stance is consistent with the positions and policies of federal agencies working toward inclusion and integration of people with disabilities in all aspects of life. For *this* whitepaper:

- *Inclusion* means providing people with autism the same community access and rights as other citizens, such as equal access to neighborhoods, community resources, and educational opportunities, as well as the right to an environment free of abuse, neglect, and harmful practices.
- **Civic engagement** means that people with autism are aware of community and civic life, have a voice in the community, and contribute fully to the community to the best of their ability (e.g., voting, participating in civic organizations, contributing to public policy development).
- **Self-Advocacy** means people with autism advocate for their own needs and provide input into decisions and policies that impact them (to the degree that their skills and comprehension allow).

### **Our Local Situation**

Local awareness of autism has increased dramatically during the past two decades, in large part through efforts of Autism McLean, Unit 5, Marcfirst, The Autism Place at ISU, and other local organizations (e.g., Easter Seals, IWU's autism group). These organizations provide autism training not only to their own staff members, but also to a wide variety of community groups (e.g., Chamber of Commerce, Rotary Club, and Kiwanis' members; local employers and human resource professionals; medical professionals; daycare providers and teachers).

There are multiple examples of collaborative local efforts that highlight ways in which autism allies and community organizations can support one another while making the community more welcoming for people

with autism. Examples include, but are not limited to (1) COUNTRY Financial's commitment in working with Marcfirst to employ people with disabilities, (2) the willingness of local business leaders to speak publically about their experiences employing people with autism, (3) the establishment of a local Kiwanis Aktion service club for adults with disabilities, (4) First Responder efforts by the Normal Police, and (5) the Autism Friendly Community initiative.

### **Unmet Needs & Action Opportunities**

Many local efforts to promote autism awareness and inclusion are carried out by autism allies and professionals on a volunteer or "after hours" basis. Volunteers (many of whom are working professionals) are often stretched thin and agency-based efforts have been greatly hampered by the Illinois state funding crisis. As a result, support for and expansion of training, civic engagement, and self-advocacy efforts is needed. Specific action opportunities include the following.

- **Expand Autism Awareness and Training Efforts**—Training needs never cease—there are always new families, new knowledge about autism, and new staff/administrators. Support is needed to ensure that an array of information, awareness, and training opportunities are available.
- Increase Self-Advocacy and Civic Engagement Opportunities within Inclusive Structures —There is a strong need to help individuals with autism build self-advocacy skills and at the same time offer social structures that encourage meaningful participation. This means
  - That schools and agencies should strengthen efforts to (a) help people with autism develop their ability self-advocate (to the degree that their skills and comprehension allow) and (b) seek meaningful involvement from people with autism in decisions and policies that affect them
  - Opening more opportunities for people with autism to participate more fully in the community
  - o Increasing awareness of and engagement in public life among people with autism
  - o Recognizing individuals with autism for their community contributions
  - Recognizing organizations for their promotion of community engagement
- Promote Involvement in Public Policy and Consider the Autism Perspectives when Planning Community Services. Significant representation of self-advocates in the policymaking process is essential to ensure both the legitimacy of the process and the creation of the most effective possible public policy strategies. For example, people with autism often face barriers to access when disability programs and services are designed without adequate understanding of autism needs. Engaging self-and autism-advocates in decision and planning processes can reduce such errors.
- Identify and Work with Allies Autism Allies include family, neighbors, professionals, business owners, cross-disability advocates, and others who support equal rights and opportunities for people with autism. Autism Allies would benefit from collaborating with other local groups working toward the goal of human rights for all people regardless of difference or disability.
- Victimization Prevention A significant obstacle for individuals with autism is their level of skill and
  comprehension related to social interactions. Consequently, they can be easy targets for scams, theft,
  fraud, and people who would take advantage of them. Police, employers, banks, and housing providers,
  among others, might undergo training to recognize signs of victimization, while learning how to deescalate conflict situations.
- Ensure sufficient public funding for Services and Supports Welcoming attitudes need to go beyond platitudes. As addressed in other sections of this report, access to needed services and community resources are essential to ensure full engagement of people with autism throughout their life span.

### Learn with me.

# Education for People with Autism in McLean County

Purpose Statement: People with autism spectrum disorders (ASD) have a wide range of educational and learning needs. This section will outline the spectrum of educational needs for people with autism, the current local situation, and opportunities to address unmet needs in McLean County.

### **A Spectrum of Needs**

Improving educational outcomes for individuals with autism is an essential element of our national policy of ensuring equal opportunity and full participation for individuals with disabilities. Congress finds the following: Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Federal laws, such as the Individuals with Disabilities Education Improvement Act [IDEA], provide protections and prescribe services for individuals with disabilities from birth through adulthood.

Under these laws, educational opportunities for individuals with disabilities have greatly expanded as have family input and demand for equity, community expectations for inclusion, access to education through electronic learning options, and Identification of effective educational practices. As a result, great strides have been made toward allowing individuals with autism to be lifelong learners.

Despite this progress, success for individuals with autism lags behind that of their non-disabled counterparts. Social isolation, bullying and legal issues greatly impact the students' ability to be successful. In addition, the rates for graduation, entry into post-secondary opportunities and success in obtaining meaningful employment all fall significantly behind those of same age peers.

### **Our Local Situation**

**Birth-to-Three direct services** are provided in home or at agency locations either by individual professionals, such as speech professionals, or by local agencies, such as Easter Seals, Marcfirst and Headstart. The current state budget has significantly reduced available services, and restrictions in eligibility requirements limit the number of individuals receiving services. The transition to school-based services as the children turn three is coordinated and allows for seamless support.

Local school districts are mandated to provide a full continuum of special education services for individuals from birth through 21, and district interpretation determines how these are implemented. Most schools have had training on autism and follow a prescribed procedure when determining needs for students with autism. But, the nature of programs offered to students with autism varies across local school districts. Most often disagreement between schools and parents revolves around "where a child will be educated" and what "level of support" is needed. Currently, there is also a financial consideration for the depth and level of special education offered.

In **preparing young people for adulthood**, schools start transition planning at age 14 ½. There is a local Transition committee (schools, agencies, parent[s], and the Regional Office of Education) that discusses and plans activities to support this effort. Marcfirst provides direct services in assisting with this process. Unfortunately, there are limited-to-no state supports available. This can be a difficult period for students with autism and their families: All services and supports are terminated upon leaving high school. There are no longer mandated programs for these young adults. They have to apply for services, and—in Illinois—need to be in crisis to receive state funding.

Each of the **post-secondary institutions** in the community (HCC, ISU, IWU, Lincoln College) have Disability Support Services Offices that provide supports for enrolled students with autism, although those supports are limited by guidelines and available financial resources of the institutions. In addition, Heartland Community College offers an educational program specifically for individuals with Developmental Disabilities, the HALO program, that is appropriate for some adults with autism.

ISU also has "The Autism Place" which provides autism training to pre-professional students, consultation to local schools, and a variety of educational services to individuals with autism. TAP has contributed greatly to local educational efforts, but the state budget crisis has affected funding streams. There are also some informal/social learning opportunities available for adults through the Normal Public Library ("Autism Café"), Vacation Bible School, Autism McLean, ISU (teen groups) and IWU (adult social group).

**Technical Trade Schools and internships** have limited opportunities, and required standards for professional certification make participation extremely difficult. Similarly, businesses are reluctant to employ individuals who graduate due to their protected status and possible need for accommodations.

### **Unmet Needs & Action Opportunities**

Needs and opportunities for action are related to training, expanding opportunities and improving the school-to-adult services transition, and support for parents and families.

### **Training Opportunities**

- **Self-Advocacy**—Individuals with autism often do not participate because they don't advocate for themselves/peers and the services they need. There is a need to enhance these skills.
- **Acceptance**—Social interaction poses significant challenges for successful integration. Working with instructors and peers on understanding and accepting students with autism is critical.
- **Individualization and Supports**—Providing information related to specific supports that meet individual student needs and skill development would help others understand and accept.

### **Expanded Learning Opportunities**

- Enhanced Transition Preparation—Many individuals with autism experience great anxiety with transition and change, and this can peak during periods of educational transitions. Targeted preparation for people with autism and the people they work and live with is essential to their success.
- Ongoing learning opportunities— Providing ongoing learning opportunities that address formal and informal learning needs is a wise community investment. The more skills developed by individuals with autism, the more opportunity they have for becoming tax-contributing citizens.
- **Electronic learning**—Learning opportunities should be made available using a Universal Design format to address both formal and informal needs.
- **Special interests**—Individuals with autism have specific interests that they perseverate on. Providing learning options related to these would enhance participation and involvement.

### **Parent and Individual Support Opportunities**

- Daycare, respite and before/after school supports are needed. Parents have few opportunities for their children to interact with peers and to have a break from the demands of raising individuals with such intense needs.
- Siblings, parents and individuals often need support, therapeutic and mental health services, which
  are extremely limited. The physical demands and emotional impact of parents' 24-7 involvement can
  be extreme. There is a great need to share with others, gain a sense that you are not alone, and share
  ideas for handling difficult situations.

# Home and Transit for me.

# Housing & Transportation for People with Autism in McLean County



*Purpose Statement:* People with autism have a wide range of needs for safe and appropriate housing and residential supports, as well as transportation enabling mobility to and from home. This section will outline the spectrum of potential housing and transportation needs for people with autism, the current local situation, and opportunities to address unmet needs in McLean County.

### **A Spectrum of Needs**

One young woman with autism described her housing needs simply: Have my own room, a quiet environment, ability to schedule my meals, a safe walk to the bus, and the ability to live with my dogs. This individual could live on her own with minimal supports, but because her family has been unable to locate affordable housing and appropriate supports in a safe, quiet location, she continues to live at home.

An older, nonverbal man with autism is unable to live at home with his aging parents due to severe perseverative behavior. Prior to moving to a group home, he completed basic household chores when provided with a picture checklist. But, group home staff say they cannot to get him to complete chores. The group home provides 24/7 supervised support, but staff have no specialized training in autism.

Although the United States Supreme Court has declared that every American with a disability has the right to live in the most integrated setting, securing appropriate housing and residential supports for adults with autism remains a major challenge. Nationally, there is a large population of adults and adolescents on the spectrum whose housing needs are not being met, typically because inadequate funding has resulted in extremely long wait lists, a lack of appropriate options, and insufficient supports. As a result, a majority of adults with autism continue to live at home, at rates even higher than adults with intellectual disabilities, while others catapult from one dire situation to the next. All need a home life that has structure, safety and stability: qualities that are especially important for individuals with autism given their preference for routine.

Individuals with autism need access to a wide range of residential options, including:

- Independent living
- Supported living supports or services provided to the individual in their family or own home
- Supervised living person lives alone or with roommates, receive more services than supported living but less than 24-hour coverage (aka, Intermittent Community Integrated Living Arrangements; CILA)
- **Community Integrated Living Arrangements** (CILA; group homes) individuals with disabilities living together in a home/ duplex / apartment in the community with 24-hour supervision

In addition, residential settings often need to accommodate the needs of people on the spectrum, such as:

- Communication and social impairments
- Preference for routines and predictability that may cause anxiety in uncertain or group settings
- A lack of understanding of others' motivations or expectations
- Cognitive or sensory issues (e.g., proximity to loud noises or traffic may cause distress)

Finally, planning residential options requires several additional important considerations such as neighborhood safety, financial support, the ability to age in place, neighborhood walkability, and access to transportation, shopping, employment, heath care, and recreation. Transportation needs, specifically, create a substantial obstacle to independent living and improved quality of life. While some people with autism are able to drive, others are limited by the multi-tasking challenges and spatial perceptions required of automobile driving. Safe, reliable, prompt transportation options are needed, especially by individuals living in rural areas and other locations not served by local transit.

In summary, the overarching need is to ensure appropriate residential and transportation options and supports for the full autism spectrum in order to facilitate quality of life and maximum independence.

### **Our Local Situation**

Residential Options in Illinois include the full range of supports from independent living to 24/7 supervision. These residential options are offered by many different service providers. Locally, residential programs are offered by Marcfirst (Intermittent and full-service CILA options that serve 15 people with autism), Homes of Hope (24-hour supports in CILA homes) and the Babyfold (residential placements for children).

Similar to the national picture, however, the waiting list for supported residential placement in Illinois is extremely long. People with ASD in Illinois do not get funding for housing unless they are on the Priority of Unmet Needs (PUNS) in Illinois, with priority going to those in crisis. Although local statistics are unavailable, with an estimated 2500 people with ASD in McLean County and only a fraction living in local residential settings, we can assume that the vast majority of individuals on the spectrum are living with their parents or other family members. This masks the high level of need that the community will face: Parents and other guardians who care for adults with autism need respite, and parents typically don't outlive their adult children.

Some people with autism qualify for transportation services within the Bloomington-Normal city limits through Connect Mobility, which serves riders with disabilities. Long wait times, the need for advance reservations and cost, however, mean that this service is not adequate for all.

The <u>McLean County Early Notification Program</u> provides important support through the Bloomington and Normal Police Departments. Local residents with disabilities may register, enabling their information to be shared with responding officers, facilitating awareness of individual situations and appropriate police response.

### **Unmet Needs & Action Opportunities**

Given the long waiting list for residential services in Illinois, including adults with autism, innovative thinking and creative funding are urgently needed. Specific action opportunities include the following.

- Increased Housing Options and Residential Support Services There is a need for a broader range of
  residential options, especially for those who could live independently and semi-independently. Plans
  are needed at the state level to address increasing needs for support services that will allow people
  with ASD to live successfully in their communities. Funded supports should include:
  - o Services and options over the entire lifespan of needs
  - o Supports to help with self-care such as meal preparation, hygiene, health care
  - Personal attendant services and assistive technology to enable people to live productively
- Increase use of McLean County's Early Notification Program Increase citizen registration and ensure law enforcement autism awareness training to minimize possible tragedies.
- Make housing options available in safe and accessible neighborhoods Ensure residences are in safe areas near public transportation or within walkable distance to employment, shopping and recreation.
- Ensure Life-long Sustainability of Appropriate Housing—Ensure long-term public funding to sustain housing and residential supports to allow people to remain in appropriate housing and obtain their highest level of independence and quality of life. Lack of such funding forces many people into nursing facilities and other institutions, greatly limiting their independence.
- Engage in Innovative Planning from The Perspective of Autism—Encourage policymakers, perhaps
  through an Autism Housing Task Force, to identify innovative housing models that could meet multiple
  community needs while taking the characteristics and needs of adults on the spectrum into account.
  (See the Appendix for Resources.)
- Transportation for people in rural areas and areas not served by Connect Transit. Consider broadening funding for the YWCA Minivan Program so it can increase services to people with autism (e.g., a service similar to Faith in Action transportation services for seniors). Future opportunities to explore include designated autism-friendly Uber drivers and a driverless cars program for people with autism.

### Wellness for me.

## **Healthcare** for People with Autism in McLean County

Purpose Statement: Disparities and gaps in health care significantly affect the lives of people with autism spectrum disorders (ASD). This section will outline the spectrum of healthcare needs for people with autism, the current local situation, and opportunities to address unmet needs in McLean County.

### **A Spectrum of Needs**

**Health is more than the absence of disease**—it also involves achieving a state of physical, mental, and social well-being (World Health Organization). People with autism often face serious challenges and barriers with respect to both aspects of this definition.

Multiple studies have shown that many serious medical conditions are more common among people with ASD than the general population, including seizures, gastro-intestinal conditions, sleep disorders and respiratory disorders. Co-occurring psychological and behavioral problems are also frequent, including higher rates of attention deficient hyperactivity disorders, anxiety, and depression. Mortality rates can be 3-10 times higher than the general population, often due to co-occurring medical conditions (Utah/UCLA Autism Epidemiologic Study Follow Up).

### Access to appropriate medical diagnosis, treatment, and wellness care is complicated by several issues:

- Adults with autism tend to be fairly poor self-reporters when it comes to health issues
- Healthcare providers may be unfamiliar or uncomfortable with autism
- Healthcare systems can be difficult to navigate
  - Individuals and families often must juggle multiple therapies and treatments
  - Autism-knowledgeable providers can be difficult to locate
  - Access to providers may be limited by lack or type of insurance coverage
- Wellness behaviors (e.g., exercise, diet) may not be taught due to more urgent needs
- With age, people with autism (as a group) tend to be fairly sedentary

Given these challenges, health providers may fail to recognize and treat serious medical conditions, mistakenly assume that symptoms are part of autism, or provide unnecessary treatments based on myths about autism. All of this creates stress for families. A recent study found that **children with ASD and a health condition had less access to appropriate medical care and more unmet needs than did other children with special health conditions.** Further, the families of the children with ASD faced significantly more **financial**, **employment and time burdens**. For example, parents of the children with ASD tended to spend 10+ hours/week on their child's treatment needs and over half had reduced or stopped work to care for their child (National Survey of Children With Special Health Care Needs).

The spectrum of needs described above underscores the critical importance of comprehensive, autism-informed healthcare for people with ASD. **Needed services include:** 

- **Diagnostic Services**—Not only to ensure an accurate and comprehensive diagnosis of ASD, but to identify any medical and behavioral conditions.
- **Treatment**—Individuals with autism typically require multiple treatments and therapies, including medical treatment for physical conditions, psychiatric/psychological intervention, speech therapy, behavioral/educational interventions, social skills training, physical therapy, and occupational therapy.
- **Wellness**—Supports are needed to teach and maintain health promotion behaviors such as hygiene skills, exercise, healthy eating, sex education, and medication management.

### **Our Local Situation**

The health care needs and experiences of children and adults with ASD in McLean County parallel the challenges and needs described in the prior section. In the area of **primary care and other medical services**, there are a limited number of local medical professionals who also have substantial knowledge of people with ASD. **Specialists in ASD** are found in major metropolitan areas such as Chicago, although there are pediatric specialists located in Peoria. **Access to transportation, level of insurance coverage, and ability to absorb extra costs all influence families' ability to access specialized medical services.** More specifically, **oral health-dental services** for people on public aid are not available. This is a community-wide concern that may impact people with ASD.

There are some **behavioral health and psychiatric supports** in our community, and a growing—if not large—number of providers who have familiarity with ASD. The ABLE Center, in Bloomington, provides neurodevelopmental assessment and psychological treatment for people on the spectrum, as do some individual therapists in town. ISU's TAP program, SkilSprout, SPICE of Marcfirst, and Easter Seals all provide clinical services to children with autism (OT, Speech Therapy, and/or behavioral treatment depending on the agency). Board Certified Applied Behavior Analysts are often sought for the treatment of young children, but their services can at times be difficult to access. Marcfirst initiated a program enabling dedicated staff to train to become Board Certified Behavior Analysts. Currently one person is certified and is working with adults.

The Autism Program (TAP) plays an important role in training pre-professional students, some of whom are in the health professions (e.g., nurses, speech language pathologists), as well as in providing consultation to health professionals in the local community. The state budget crisis, however, has disrupted TAP's funding.

### **Unmet Needs & Action Opportunities**

Specific action opportunities include the following:

- Teaching Providers About Autism Needs: Some health care providers lack sufficient familiarity with the
  needs of the ASD population. Continuing education requirements for health care providers can improve
  awareness of autism life span needs. Professional licensing boards should take action against unethical
  providers who exploit clients by marketing products and treatments lacking valid scientific basis.
- Work to ensure more equal access to needed diagnostic and treatment services—Access to services
  depends too often on family resources (financial, insurance, transportation) rather than on the health
  needs of the person with autism. The Department of Public Health may be able to play a key role in
  outreach to families to improve access to health care for all individuals with autism.
- Identify mechanisms for creating a *County Wide Directory of Services for People with Disabilities* For several years, the forerunner to Autism McLean compiled and published the *T.R.A.I.N.* resource booklet that identified local service providers that were autism friendly. The resource was valuable, but time intensive for a volunteer agency to maintain. The Regional Planning Commission might take the lead in coordinating a *County Wide Directory of Services for People with Disabilities*.
- Recruit for and consider autism expertise when hiring new medical staff—The presence of more medical professionals with experience in developmental disabilities and autism would improve healthcare for local citizens with autism. Further, major local medical providers (e.g., Advocate BroMenn/OSF) might benefit from a master's level autism or developmental disabilities specialist to consult with primary physicians and medical specialists in the course of client care.
- Educate families about the helpfulness of the ASD diagnosis—Some parents resist getting a clinical diagnosis for various reasons. Parents may need to learn how diagnosis improves access to appropriate educational services and how timely diagnosis is essential for obtaining services across the life span.
- Assess needs and coordinate resources for autism-related aging issues such as palliative care, hospice, dementia and nursing home supports. There is little information about standards of care or training available to support individuals with ASD in these situations. Anecdotal reports reflect unique behavioral challenges that can be difficult for these health care teams to address appropriately.

# Work with me.

## **Employment** for People with Autism in McLean County

Purpose Statement: People with Autism (ASD) are often the most underemployed and unemployed group of people in our nation. This section will outline the spectrum of employment needs for people with autism, the current local situation, and opportunities to address unmet needs in McLean County.

### **A Spectrum of Needs**

Low levels of employment for people with ASD are well documented, with rates typically falling far below even those of adults with other disabilities (National Autism Indicators Report). Some estimates suggest that up to 90% of people with autism are either unemployed or underemployed. Although autism characteristics—such as social-communication impairments and perseverative behaviors—can create challenges in the workplace, adults with ASD are high-potential employees.

Multiple demonstration projects have shown that people with ASD can be productive employees, valued for their skill with complex repetitive tasks, adherence to procedures, and reliability. While adults with autism gain benefits from employment, such as financial stability and improved quality of life, there are also important benefits for businesses. For example, Walgreen's distribution facility, staffed by employees with autism, exceeds the highest productivity standards.

Current national guidelines emphasize the importance of competitive employment for people with disabilities. For example, federal guidelines specify that people with intellectual or developmental disabilities (1) must be offered employment as a first choice for day services and (2) that this excludes work paid at a subminimum wage and/or in segregated settings (Home and Community Based Services Medicaid Guidelines). The Division of Rehabilitation Services provides funding to help citizens with disabilities locate and maintain such employment. But, individuals can only receive 24 months of services, and federal funding cannot be extended to provide the long-term supports that many individuals with ASD need. Implementation of the federal Workforce Innovation and Opportunity Act (WIOA) may open new opportunities for job seekers with disabilities to access employment services.

One important evidenced-based approach to helping people with autism obtain employment is Customized Employment (CE), which matches a specific job candidate's strengths to a specific employer's needs. Once a position is developed, the employee with autism is coached by a job facilitator to learn job tasks and expectations. Recent studies suggest that successful employment is more likely for people with autism when they receive CE/supported employment services delivered with an understanding of autism. Accommodations and supports for employees with autism are typically low-cost and easy to implement, such as establishing routines, using visual schedules, and providing coworker training.

### **Our Local Situation**

In Illinois, only 6% of individuals with intellectual/developmental disabilities (I/DD) are employed in integrated settings (versus 25% nationally; Illinois Employment First Blueprint, 2014). The need for better practices around employment for individuals with disabilities was highlighted when Illinois approved *Employment First* legislation (2013). The plan for implementing this legislation includes:

- Prioritizing and increasing integrated community employment for people with disabilities
- Making disability employment part of the state workforce development strategy
- Finding and supporting businesses in their efforts to employ people with disabilities
- Strengthening transition services and the infrastructure needed to meet these goals
- Establish benchmarks and collecting data to track employment outcomes

In Mclean County, **employment services** are offered by Marcfirst, United Cerebral Palsy, DRS, and Bridgeway. All of these agencies have been open to training to help them better serve clients with autism. At any given time, between 35 and 40% of the individuals in Marcfirst's employment program are living with ASD. *Opportunity Country* is a collaborative effort between Marcfirst and COUNTRY Financial. The program has successfully used an **internship-to-work model** to help five individuals with disabilities find successful careers at COUNTRY. One of these employees has ASD. The Autism Friendly Community initiative recently recognized over 15 local employers for hiring people with autism, including the Marriott Hotel in uptown Normal, Avanti's, La Gondola, COUNTRY Financial, Heritage of Health, TA Travel Center, Kroger, Wal-Mart, Snyder Companies, Freedom Oil, Starplex Cinema, Bridgeway, Pheasant Lanes, and AFNI.

### **Unmet Needs & Action Opportunities**

Despite dedicated local efforts and some important local successes, needs related to employment for people with autism continue to be urgent in McLean County. Disability employment is not well integrated into county workforce development strategies, finding a sufficient number of community employers willing to hire individuals with autism has been challenging, the post-high school transition process seldom leads smoothly to integrated employment, and data on employment for adults with autism in McLean County is lacking. Specific opportunities for meeting needs include the following:

- Expand Autism-Informed Customized Employment and Supported Employment Services—Local
  agencies need support to maintain and expand effective programs, such as Opportunity Country, so
  that more clients can be served. Agencies need funding streams in order to train and certify their staff
  in state-of-the-art vocational support models as well as in strategies tailored for clients with autism.
   Further, because job turnover reduces program effectiveness, agencies need sufficient funding to retain
  trained and experienced staff.
- Expand communication with and support for local employers with the goal of increasing work
  opportunities in many sectors Ongoing communication and education is critical to opening
  opportunities for people with autism to work in our community.
  - o Form a speaker's group that can present to groups and employers regarding the benefits of people with autism being in the workforce.
  - Create a tool kit for local employers interested in hiring people with autism, including contact information of employers who hire people with disabilities, training videos and more.
  - Provide training and consultation on using autism-friendly supports and accommodations (e.g., visual cues, mentors, quiet work environment).
  - o *Continue Recognizing Autism Friendly Businesses*. Local businesses deserve to be recognized—via municipal awards, local media or other venues—for their work in hiring people with autism.
  - Identify allies in local government entities. The hiring of adults with ASD by local government entities would send a uniquely strong message about the degree to which our community welcomes people with autism.
- Identify Innovative Funding Structures for Long Term Employment Support Many adults with autism need extended, even lifelong, employment support services. Because federal funding (DORS) stops after 24 months, agencies must find local or innovative resources to continue
- Increase collaborative work with educational entities Areas of important focus include improving the high-school-to-work transition and identifying areas of projected job growth so that schools can teach skills related to these areas of opportunity (e.g., technology). The most important activity to help students transition to paid employment after graduation is to work in paid employment while in school.
- **Creative Entrepreneur Development** Some people with autism may have the potential to go into business for themselves. Consider partnerships and collaborations with local entrepreneurship resources, such as business incubators.

# Play with me.

# Recreation for People with Autism in McLean County



*Purpose Statement:* People with autism spectrum disorders (ASD) have a wide range of needs for inclusion in existing recreational offerings as well as for specialized services and activities. This section will outline the spectrum of recreation and leisure needs for people with autism, the current local situation, and opportunities to address unmet needs in McLean County.

### **A Spectrum of Needs**

Like everyone, people with autism have needs for recreational, leisure, athletic and social opportunities. Recreational activities provide essential opportunities for people with autism to develop social relationships and skills. Further, engaging in preferred activities can reduce anxiety and behavioral challenges. Accessible recreational opportunities are needed across the life span. For example, many children with autism find free-flowing social play confusing, and opportunities to learn and practice play skills are needed. For adults, especially for those that are under- or unemployed, recreational activities can provide a greatly needed sense of structure and purpose.

Some people on the spectrum do well in existing programs and settings. Many find leisure activities--like bicycling or going to a museum—enjoyable and restorative. Many people with autism are routine or rule oriented, so may function well in gyms, exercise or sport settings that emphasize rules. Most people with ASD enjoy some form of social interaction, especially when shared interests are involved.

**Fitting into recreational settings can be challenging for people on the spectrum.** Loud noises and other aspects of the setting may be over-stimulating. This is a constant tension for many: They may like the setting, but also find it overwhelming. In other cases, "stimming" behavior, like arm flapping, can distract or draw inappropriate reactions from others. Communication impairments also pose challenges. For example, an individual may have difficulty with conversational give-and-take between activity participants or misunderstand the teasing that teammates often direct at one another. Other individuals with autism have additional physical or developmental conditions that require support.

Recreational settings often need to be modified to make them more welcoming for people with autism. Effective modifications include: (1) sensory accommodations, such as movie showings with dimmed lights and reduced sound, (2) after hours events, where caregivers can worry less about how others will react to the individual with autism, (3) safety perimeters to ensure an individual cannot wander off and be exposed to potential dangers, (4) having mentors help people on the spectrum learn to socialize, and (5) ensuring a welcoming, tolerant environment.

Given the wide range of characteristics associated with autism, access to a spectrum of recreational opportunities is needed. This includes opportunities specialized for people on the spectrum as well as inclusion in non-specialized community programs (with modifications if needed).

### **Our Local Situation**

In McLean County, there are several excellent recreational programs that welcome people with autism. Most are oriented toward youth or young adults, rather than those who are older. These include, but are not limited to, the following opportunities:

**Local Recreational Opportunities** include three autism-focused camps sponsored by *Autism McLean*, leisure activities sponsored by *Special Opportunities Available in Recreation (SOAR)*, and autism-friendly theater projects (e.g., *Penguin Project*, *Seedling Encore*). In addition, individuals with autism are welcomed in some local interest/hobby groups (e.g., gardening group, local music groups).

**Local Athletic Opportunities** include bowling, open gym times, track and field, basketball, baseball, and a variety of other sports sponsored by *Autism McLean, SOAR, Special Olympics*, the *Lions Cheer Company*, and the *Miracle League*. Occasionally, local youth with autism participate in their schools' sports programs.

**Local Social Interaction Opportunities** include buddy or peer programs in which people with autism are paired with mentors for social activities (e.g., ISU TAP autism social groups for children; IWU autism social group for adults; Best Buddies at ISU, IWU and area high schools). In addition, the *Normal Public Library* hosts an "Autism Café," for adults on the spectrum, and *Eastview Christian Church* has a support group for families and individuals on the spectrum.

### **Unmet Needs & Action Opportunities**

Local recreational programs have been well received, but are not sufficient to meet local needs. Programs are often limited by capacity, funding, or challenges associated with volunteer-based grassroots efforts (e.g., finding enough volunteers). More opportunities are needed to address the community's growing needs, including (a) support for specialized programs so that they can maintain or expand opportunities and (b) identification of more "allies" willing to adapt their recreational settings/activities to make them more accessible to people with autism.

### Some specific opportunities for action include

- Increase integration into existing Boy Scouts or Girl Scouts programs, either through training to help troops to be autism-friendly, or, perhaps, through developing autism-focused troops.
- Provide autism-focused training to increase the availability of volunteers to work with this population, especially for groups like Big Brother/Big Sisters.
- **Develop creative programs to meet recreational needs**. For example, museums and similar institutions could develop programs that involve people with autism (see, for example, NYC's transit museum's "Subway Sleuths" after-school program).
- Complement the existing autism-friendly athletic programs, by offering more athletic opportunities related to swimming, ice-skating/hockey, martial arts, soccer, and fitness.
- Further expand autism-friendly opportunities for visual and performing arts, perhaps through creative collaboration with local galleries, artists, music/theatre programs, and so forth.
- Create clubs for people on the spectrum that tap their specialized interests and draw them into social interaction, particularly with non-autistic community members (e.g., Lego, computer programming, anime, science topics, transportation, Harry Potter).
- Work to make outdoor recreation and leisure spaces more autism-friendly, especially for more severely-impacted individuals. This could include a playground areas surrounded by fencing, to ensure that children who are prone to wandering off are kept within a safe zone.

A bigger dream: A place to call our own. A major difficulty with programming activities is the need to locate space at existing facilities. A community center for autism could be very useful. This could include multi-use space for meetings, social clubs, exercise sessions, and respite nights. There could be a garden or other outdoor facilities that could help people on the spectrum feel productive. This effort would benefit from multi-agency collaboration, and could perhaps dovetail with efforts to address housing needs. For example, a mock apartment at the center could help facilitate training in self-sufficiency and self-care, or this center itself could be part of a housing or apartment complex welcoming people on the spectrum.

# **Appendix**

Following is supplemental information and resources related to each of the major sections of this whitepaper.



### Local resources providing services and supports for people with autism:

(not a comprehensive list)

| Organization   | Welcome | Education | Housing | Healthcare | Employment | Recreation |
|--|---------|-----------|---------|------------|------------|------------|
| Autism McLean  | Х       | х         |         |            |            | х          |
| Baby Fold—Hammitt School                                 |         | х         | Х       |            |            |            |
| Best Buddies   |         |           |         |            |            | х          |
| Bloomington/Normal Police—<br>Early Notification Program |         |           | х       |            |            |            |
| Bridgeway  |         |           |         |            | x          |            |
| Div. of Rehabilitation Services                          |         |           | Х       |            | x          |            |
| Easter Seals   | Х       | x         |         | x          |            | х          |
| Eastview Christian Church—family support group           |         |           |         |            |            | х          |
| Headstart  |         | х         |         |            |            |            |
| Heartland Community College                              |         | х         |         |            |            |            |
| High Roads   |         | х         |         |            |            |            |
| Homes of Hope  |         |           | Х       |            |            |            |
| ISU  |         | х         |         |            |            | х          |
| IWU's autism social group                                | Х       |           |         |            |            | х          |
| Kiwanis Aktion Club                                      |         |           |         |            |            | х          |
| LifeCIL  |         |           |         |            |            |            |
| Lincoln College  |         | х         |         |            |            |            |
| Marcfirst—includes Spice                                 | Х       | х         | Х       | х          | х          | х          |
| Miracle League   |         |           |         |            |            | х          |
| Normal Public Library                                    |         | х         |         |            |            | х          |
| Penguin Project  |         |           |         |            |            | х          |
| School districts   | Х       |           |         |            |            |            |
| Seedling Encore  |         |           |         |            |            | х          |
| SkillSprout  |         | х         |         | х          |            |            |
| Special Olympics   |         |           |         |            |            | х          |
| Special Opportunities Available in Recreation (SOAR)     |         |           |         |            |            | х          |
| The Able Center  |         |           |         | Х          |            |            |
| The Autism Place—ISU                                     | Х       | Х         |         | Х          |            |            |
| The Lions Cheer Company                                  |         |           |         |            |            | Х          |
| Transition Committee                                     | _       | Х         |         |            |            |            |
| United Cerebral Palsy                                    |         |           |         |            | х          |            |

### Supplemental Information: Overview & Introductory Sections

#### **Additional Information about Autism**

Source: http://autisticadvocacy.org/home/about-asan/about-autism/

Autism is diagnosed based on observation by a diagnostician or team of diagnosticians (e.g. neuropsychologist, psychologist, psychiatrist, licensed clinical social worker, etc.). While all people with autism are as unique as any other human beings, they share some characteristics typical of autism.

- **1. Different sensory experiences.** For example, heightened sensitivity to light, difficulty interpreting internal physical sensations, hearing loud sounds as soft and soft sounds as loud, or synesthesia.
- 2. Non-standard ways of learning and approaching problem solving. For example, learning "difficult" tasks (e.g. calculus) before "simple" tasks (e.g. addition), difficulty with "executive functions," or being simultaneously gifted at tasks requiring fluid intelligence and intellectually disabled at tasks requiring verbal skills.
- **3. Deeply focused thinking and passionate interests in specific subjects.** "Narrow but deep," these "special interests" could be anything from mathematics to ballet, from doorknobs to physics, and from politics to bits of shiny paper.
- **4. Atypical, sometimes repetitive, movement.** This includes "stereotyped" and "self-stimulatory" behavior such as rocking or flapping, and also the difficulties with motor skills and motor planning associated with apraxia or dyspraxia.
- **5. Need for consistency, routine, and order.** For example, holidays may be experienced more with anxiety than pleasure, as they mean time off from school and the disruption of the usual order of things. People on the autistic spectrum may take great pleasure in organizing and arranging items.
- 6. Difficulties in understanding and expressing language as used in typical communication, both verbal and non-verbal. This may manifest similarly to semantic-pragmatic language disorder. It's often because a young child does not seem to be developing language that a parent first seeks to have a child evaluated. As adults, people with an autism spectrum diagnosis often continue to struggle to use language to explain their emotions and internal state, and to articulate concepts (which is not to say they do not experience and understand these).
- 7. Difficulties in understanding and expressing typical social interaction. For example, preferring parallel interaction, having delayed responses to social stimulus, or behaving in an "inappropriate" manner to the norms of a given social context (for example, not saying "hi" immediately after another person says "hi").



### Supplemental Information: Welcome Me

#### A Note on Defined Terms

The **Welcome Me** section provides working definitions of the terms *inclusion*, *civic engagement*, and *self-advocacy*. We acknowledge that these terms refer to complex ideas that can be defined in different ways. For example, the term "self-advocacy" has multiple meanings. It can refer to an individual's efforts to direct his or her own life, be it at home, at school, at work or in relationships. It can also refer to the efforts of a group or community to direct the public policy, media, societal, and other conversations and actions about that community.

Local Organizations Advocating for People with Autism in McLean County

- Autism Friendly Community autism awareness collaborative campaign of Autism McLean & Marcfirst
- Autism McLean (formerly Autism Society of McLean County)
- Marcfirst
- Easterseals Central Illinois
- Heroes Embracing Autistic Lives, Inc. (H.E.A.L. foundation)
- The Autism Program of Illinois

**Federal Agencies and Organizations.** Federal legislation, policies, and agencies guide and support a variety of services for people with disabilities. These are just a few starting points.

- National Council on Disabilities <a href="http://www.ncd.gov/about">http://www.ncd.gov/about</a>: Organization that advises president on national policy related to disability
- <a href="https://www.disability.gov/">https://www.disability.gov/</a> The US federal government website for information on disability programs and services.
- <a href="https://www.dol.gov/odep/">https://www.dol.gov/odep/</a> Office of Disability & Employment Policy (ODEP) of the US Department of Labor. ODEP promotes policies at all levels of government to increase workplace success for people with disabilities.

### Supplemental Information: Welcome Me (cont.)

### **Expanded List of Potential Autism Awareness and Training Opportunities**

- Expand awareness of autism by providing general information or resources about autism
  - o Creation and dissemination of basic information about autism and autism resources
- Provide relevant information and training within the autism community
  - Provide people with autism, their families, and people that serve this population with information about
    - local autism support organizations
    - autism-friendly activities
    - autism-friendly businesses and services
  - Provide autism-focused training and consultation to organizations that directly serve people with autism
    - Training about autism for employees and volunteer staff
    - Training staff to recognize and respond to common autistic behaviors
    - Training staff about effective accommodations
- Provide training to general businesses, services providers and organizations
  - o Training may be offered to volunteers, staff, clients, etc.
  - Basic informational training is needed to address
    - How to offer a welcoming environment in which individuals with autism and their caregivers feel respected, understood, and welcome
    - How to create a more positive customer/client experience
    - How to communicate that you are autism-friendly
  - Example Banks might offer staff training so that their employees can better help customers who have autism to safely manage their finances and avoid scams.
  - More advanced training and follow-up consultation can address
    - How to modify the environment to make it more autism friendly (e.g., identifying and addressing sensory issues for the site)
    - Identifying and making needed accommodations specific to the business or site with the goals of increasing the understanding and safety of people with autism, such as:
      - Providing clear instructions, routines and visual supports that can be easily understood by people with autism
      - Identifying and addressing possible safety hazards (e.g., identifying possible dangers and making plans to minimize them)
    - Example Police can undergo continued training to recognize signs of autism and victimization, while learning how to de-escalate conflictual situations
- Provide support for carrying out autism awareness activities
  - o Financial—funding to cover costs related to staff, materials, space rental, etc.
  - Staff (volunteer and paid)—people are needed to advertise awareness/training activities, to create materials/websites, distribute material, and provide training. General education can often be done by volunteers from various organizations. Advanced training and follow-up consultation are often provided by paid professionals, given the need for greater expertise, preparation and time-commitment.
  - o Materials—flyers, websites, demonstration materials for training, etc.
  - Space—places to create and distribute information, places to hold training

### Supplemental Information: Education

#### Major Federal Laws guiding education for individuals with disabilities are:

- The Individuals with Disabilities Education Improvement Act [IDEA]
- Americans with Disability Act (ADA)
- Section 504 of the Rehabilitation Act
- Every Student Succeeds Act (ESSA)



### Supplemental Information: Healthcare & Wellness

### SOURCES — Co-Morbidity of Medical Conditions and Treatment Concerns

- Kohane, I.S., McMurry, A., Weber, G., et al. (2012) The Co-Morbidity Burden of Children and Young Adults with Autism Spectrum Disorders. *PloS one*, 7(4), e33224.
- Isaksen, J., Bryn, V., Diseth, T.H., et al. (2012). Children with autism spectrum disorders—The importance of medical investigations. *European Journal of Paediatric Neurology, 17 (1),* 68-76.
- Bilder, D., Botts, E.L., Smith, K.R., et al. (2013). Excess Mortality and Causes of Death in Autism Spectrum Disorders: A Follow up of the 1980s Utah/UCLA Autism Epidemiological Study. *Journal of Autism and Developmental Disorders*, 43(5), 1196–1204.
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- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, 122(6), e1149-e1158.

### **SOURCES** — for educating families and healthcare providers

- Autism Speaks transition tool kit on health issues at <a href="https://www.autismspeaks.org/sites/default/files/docs/ttk2\_health.pdf">https://www.autismspeaks.org/sites/default/files/docs/ttk2\_health.pdf</a>
- Medical Comorbidities in Autism Spectrum Disorders A Primer for Health Care Professionals and Policy Makers (from Treating Autism and Autism Treatment Trust) at http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf



### Supplemental Information: Employment

### Sample Employment Statistics for Adults with ASD

- 90% of adults with autism are unemployed or underemployed (International *Board of Credentialing and Continuing Education Standards, July 8,2015*)
- Only 53.4% of young adults with ASD surveyed ever worked for pay outside the home within the first 8 years after leaving high school. Only 20% work fulltime at a current or their most recent job with the average wage being \$8.10 per hour. (Young Adults on the Autism Spectrum Face Tough Prospects for Jobs and Independent Living; Journal of the American Academy of Child and Adolescent Psychiatry)
- We were unable to locate statistics on the employment of adults with autism in Mclean County. But rough estimates can be made based on data suggesting that
  - o 90% of adults with ASD are under- or unemployed
  - o about 135,000 age 18 and over live in McLean County (www.census.gov)
  - about 1 in 68 people meet criteria for a diagnosis of ASD
     Using these parameters, we can estimate (roughly) that about 1950 adults with ASD live in
     McLean County, and that 1750 of these individuals are either underemployed or unemployed.

### Benefits of Hiring People with Autism Identified in the Literature

#### **Business/Organizational benefits:**

- Gain reliable, loyal and effective employee
- Progress towards meeting diversity goals
- Raise awareness of diversity among its staff
- Managers with understanding of ASD communication difficulties learn communication skills that help their whole team.
- Accommodations and awareness can increase co-worker productivity.
- Improved internal and external PR
- Non-autistic employees are freed from tedium of complex, repetitive tasks.

#### Desirable skills and qualities that people with autism bring to the job:

- Reliable, hardworking and motivated to work
- Attention to detail
- Adherence to established rules and procedures
- Maintain a high level of accuracy
- Good performance on complex, repetitive tasks
- Honesty and straightforward directness
- Many have advanced technical skills
- Some have academic degrees
- Good retention of facts and figures
- Often prefer work to socializing
- Strong loyalty to their employer

### Supplemental Information: **Employment** (cont.)

### Strategies for Identifying Employment Sectors & Potential Jobs for People with Autism

As projected job growth areas are reported, it is important to develop people with autism to have skills to fill these opportunities for employment. Projected Job growth between 2014 and 2024 (Employment Projections, US Bureau of Labor Statistics)

| • | Software Developers applications | 18.8% |
|---|----------------------------------|-------|
| • | Computer Systems Analysts        | 20.9% |
| • | Accountants and Auditors         | 10.9% |
| • | Management Analysts              | 13.6% |
| • | Janitors                         | 5.8%  |
| • | Construction Laborers            | 12.7% |
| • | Maintenance and Repair workers   | 6.1%  |
| • | Stock clerks                     | 4.9%  |

# Jobs that utilize the unique strengths and tendencies of people with ASD offer the best opportunities for success. While individual abilities vary, many people with ASD flourish in jobs which utilize:

- clear procedures and systems, such as filing, digital imaging, inventory maintenance, library and archive work, computer programming, and assembly line production
- attention to detail and accuracy, such as data entry, filling orders, technical writing, editing, proofreading, bookkeeping and medical coding
- analytical skills and logic, such as software testing and research
- creative thinking and arts
- independence and solo tasks
- hyperfocus
- their natural interests and abilities

#### **SOURCES**

- Hagner, D., & Cooney, B. F. (2005). "I do that for everybody": Supervising employees with autism. *Focus On Autism & Other Developmental Disabilities*, 20(2), 91-97.
- Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation*, *32*(2), 125-134
- Illinois Employment First Blueprint: Equip for Equality (October 2014) available at <a href="http://www.equipforequality.org/wp-content/uploads/2014/10/Equip-for-Equality-Employment-First-Blueprint.pdf">http://www.equipforequality.org/wp-content/uploads/2014/10/Equip-for-Equality-Employment-First-Blueprint.pdf</a>
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### Supplemental Information: Home and Transit

### **Additional Considerations when Planning Housing**

In planning and selecting housing options for people with autism, it is important to consider autism characteristics and effective practices for supporting people with autism (e.g., visual instruction, environmental modifications, use of communication systems, routines). Additional important considerations include:

- Location, neighborhood walkability, and access to transportation are important, as they provide access to food, shopping, employment, health care, and recreational opportunities.
- **Safety** safe neighborhoods and safe housing are a necessity. Some people with ASD may lack a sense of danger or the ability to react appropriately in potentially dangerous situations. People with ASD are an easy target of bullying and crime.
- Financial support access to financial means and the ability to manage finances
- Sensory needs Noise may be an issue (e.g., proximity to high traffic areas)
- **Ability to Age in Place** as people with ASD find routine and comfort in their living arrangements, homes should allow the person to live there indefinitely

### Illinois and Local Agencies providing residential options and resources include:

- Autism Speaks provides a listing of all programs in Illinois, and other states, that provide residential services at <a href="https://www.autismspeaks.org/housing-catalog?province=IL">https://www.autismspeaks.org/housing-catalog?province=IL</a>.
- Marcfirst offers residential services in Bloomington-Normal. Services include:
  - Intermittent CILA Supports to provide supports for people with ASD living in an apartment or home. Services would be approximately 15 hours a week, up to 39 hours depending on the person's need.
  - Twenty-four hour CILA supports in residential settings including apartments, duplexes and homes throughout Bloomington/Normal.
- Babyfold offers residential placements for children with ASD.
- **Homes of Hope** offers twenty-four hour supports in CILA homes.

### **Online Resources for Innovative Planning:**

Autism Speaks offers a **Housing Tool Kit** to assist individuals and families (and possibly communities such as ours) as they identify and seek to expand appropriate residential supports and services.

- https://www.autismspeaks.org/family-services/housing-and-community-living
- https://www.autismspeaks.org/sites/default/files/housing tool kit web2.pdf

Autism Speaks' **2016 House to Home Competition** attracted more than 250 competitors from 63 countries who submitted innovative, multifaceted ideas for developing alternative housing and support services for the growing number of adults with autism spectrum disorder (ASD).

 https://www.autismspeaks.org/about-us/press-releases/autism-speaks-unveils-house-home-prizewinners

The Autism Housing Network promotes creative models for addressing housing needs: <a href="http://www.autismhousingnetwork.org/about/">http://www.autismhousingnetwork.org/about/</a>

A sample state (PA) sponsored investigation into housing models for People with Autism is available at <a href="http://delco-network.wikispaces.com/file/view/Housing\_Options\_for\_Adults\_with\_Autism\_-\_FINAL\_-\_05-20-10.pdf">http://delco-network.wikispaces.com/file/view/Housing\_Options\_for\_Adults\_with\_Autism\_-\_FINAL\_-\_05-20-10.pdf</a>

### Supplemental Information: Recreation

### An Expanded List of Local Recreational Activities that Welcome People with Autism

(Note: This list is not comprehensive. Omission of specific programs or opportunities in no way implies negative judgment of that opportunity.)

### **Local Recreational Opportunities**

- Autism McLean sponsors three autism camps, one for people ages 6 to 22 (Takoda Camp), one for those over 18 (iAM Social Camp), and one for siblings (Camp Pathfinder).
- Special Olympics & Recreation (SOAR) sponsor arts and crafts, cooking, and community outings.
- The Penguin Project and Seedling Encore involve people with autism in theatrical performances.
- Individuals with autism are welcomed in some local interest/hobby groups, including a gardening group, local music and vocal groups, and community drama productions.

### **Local Athletic Opportunities**

- Autism McLean sponsors autism-friendly bowling, basketball, backyard games and open gyms.
- SOAR has bowling, tennis and volleyball and works with Special Olympics for track and field, gymnastic, soccer, basketball, weight lifting and a variety of other sports.
- The *Miracle League* (at Heartland Community College) offers baseball leagues for those with developmental needs and The *Lions Club* has a Cheerleader program for girls.

### **Local Social Interaction Opportunities.**

- Illinois State University works with Marcfirst to offer a "Best Buddies" program and ISU's TAP program runs some social interaction groups for children and teens with autism.
- Illinois Wesleyan University has its Autism Social Group, where adults on the spectrum are partnered with IWU students for a variety of activities.
- Normal Community High School offers another Best Buddies program.
- The *Normal Public Library* hosts an "Autism Café," where adults on the spectrum, friends and care givers can discuss situations, engage in social activities, and enjoy time together.
- Eastview Christian Church has a support group for families and individuals on the spectrum.

# Some creative and inspirational recreational programs that could serve as models for local efforts are: (See Autism Speaks provides an overview and links to a wide variety of recreational and social programs: <a href="https://www.autismspeaks.org//search/apachesolr\_search/recreation">https://www.autismspeaks.org//search/apachesolr\_search/recreation</a>)

- Erin's Hope for Friends http://erinshopeforfriends.org
- <u>Creative Living, Inc.</u> for adults with developmental disabilities through respite, life skills, social, educational and **recreational** programs.
- Art Enables creates the opportunity for visual artists with disabilities to make and market their honest and compelling work.
- YMCA in Lino Lakes Special Needs Swim Instruction —
   http://www.ymcatwincities.org/locations/lino\_lakes\_ymca/swimming\_and\_aquatics/sw...
- Boston Conservatory Programs for Students on the Autism Spectrum music programs for individuals on the autism spectrum
- Picasso Einstein http://www.picassoeinstein.com
- <a href="http://web.mta.info/mta/museum/)--NYC's">http://web.mta.info/mta/museum/)--NYC's</a> transit museum's recognized after-school program for children with autism ("Subway Sleuths")

