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Creating Collaborative Lifelong Solutions: Person, Family, Professionals, and Community

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Across the United States, two million families are struggling to create supports for their loved ones with an intellectual disability and mental illness (Easter Seals, 2008). This same trend is being seen in the State of Maine where there are an increasing number of youth diagnosed on the Autism spectrum with a co-morbid mental health disorder. Specifically, the Department of Health and Human Services reports that Maine Care recipients with Autism and related disorders in 2009, numbered 4156 (Richardson, 2011), with those entering adulthood in the fastest growing group. As we look to the future, there are over 2500 individuals between the ages of 6-17 years currently diagnosed with an Autism Spectrum Disorder (Richardson, 2011). Nationwide, we know that 80% of those with a developmental disability between the ages 19-30 live with their parents, as few other choices exist outside institutionalization. Meanwhile, nationwide, 500,000 children with an Autism Spectrum Disorder are expected to reach adulthood in the next 15 years (Diament, 2010), 1 in 5 families with an adult child with developmental disabilities state that someone had to quit their jobs to provide care, and 80% of caregivers of adult children with developmental disabilities have put their retirement savings in jeopardy (Diament, 2011). Additionally, the statistics highlight many individuals with a developmental disorder (such as Autism) also have a co-morbid mental health diagnosis. Mental health problems faced by this population include anxiety, depression, and behavioral disorders (Mueller & Prout, 2009).

Statement of Need

Adult Services in the State of Maine continue to face serious challenges in meeting the program and support needs for young people with developmental disabilities as they transition from Children's Services. Parents, young adults, educators, mental health providers, advocates, stakeholders, and Department of Health and Human Service (DHHS) representatives have identified issues of transition from school-based services toward adult roles, including: lack of a unified transition plan, inefficient and confusing referral process/system, inadequate funding

across the lifespan, limited coordination between educational/vocational/mental health and related services, unsuitable housing options, and a need for parent education on the service delivery systems (Cronin, 2008). There are currently 680 Maine adults with Autism or other related disabilities waiting for Maine Care funding for some level of service, 180 of these are considered to be "in critical need because of health and safety concerns" (Richardson, 2011, p. A1, A13).

There are limited options for young adults with developmental disorders and mental health issues. As the lack of options and opportunities for young adults with Autism Spectrum Disorder (ASD) continues to create serious difficulties for families, parents are coming together to create innovative options by purchasing housing units and finding ways to allow for shared living with live-in supports (CBS News, 2007). Families are creating options by finding condominiums with shared common space for their adult children with developmental disabilities (20 E Street, 2011).

In the State of Maine, there are limited options for young adults with significant intellectual disabilities/Autism/mental health disorders. Those in critical need may qualify for the most comprehensive level of services. However, most families are doing the best they can with limited resources and supports while the young adult with Autism must deal with occupational and social deprivation. Young adults with autism watch while their typical peers move on to jobs, college, and adult social relationships while they become increasingly in need of outlets that would allow them to experience productivity, independence, and socialization outside of the family unit (Tomchek & Case-Smith, 2009).

The long-term picture is concerning. The estimate, based on parental report, is that there are more than 20% of families caring for someone with Autism who have no plan for the future. There are over 711,000 adults with ASD currently being cared for by people over the age of 60 (Autism Society, 2009).

Transition to Adult Life

While there is limited information on the long-term outcomes for adults with high functioning

ASD (Bauer, 1996), the following have been identified as important factors in a successful transition to adult life:

- Having a guiding and supporting mentor who understands the individual and his or her unique needs
- A friend or intimate partner who provides elements of support, belonging, and affection to the person to compensate for his or her peculiarities.
- Meaningful work or productivity in his or her area of special interest can help to offset the social challenges associated with ASD (Attwood, 1998).
- Disability awareness can assist the young adult to come to terms with his or her strengths and deficits assisting the young adult to no longer want to become someone he or she cannot be and realizing he or she has qualities others admire (Journey & Loukas, 2008; Kielhofner, 2008).
- "A natural recovery. As much as there are late walkers or talkers, there can be late socializers, although late can be by several decades" (Attwood, 1998, p.182-183).

Any program that purports to promote successful independent or inter-dependent living for adults with Autism and Asperger's Disorder must address social participation, instrumental activities of daily living such as bathing/showing, meal preparation and clean-up, learning manners, personal hygiene and grooming, financial management, driving and community mobility, shopping, sexual etiquette, and safety (American Occupational Therapy Association, 2008; Gooden-Ledbetter, Cole, Maher & Condeluci, 2007). The cooking, cleaning, and hygiene aspects of daily life are referred to as the "magnificent mundane" in the occupational therapy literature, indicating the importance of these basic every day activities (Chandler, Schoonover, Clark, & Jackson, 2008). Young adults with Autism need assistance to develop their unique areas of strengths, move beyond their obsessive interests, expand upon their skills, find mentors, develop good work skills, socialize through shared interests, try new things, limit television and video games, and learn social relatedness (Grandin, 2009; Tomchek & Case-Smith, 2009).

Therapeutic Intervention for Young Adults with ASD

Historically, young adults with developmental disabilities not living with their families resided in homes of six or more (Hulgin, 1996; Hulgin &

Walker, 1997) in a congregate model of care. Port Resources (PR) in Portland, Maine has a unique approach to supportive living that enables individuals with developmental disabilities to develop their competencies and explore with the person what options he/she has for long-term living. PR will work to redirect resources to an individualized supported living plan and not rely on the long-term congregate care model. This could include, but is not limited to, living alone, with a roommate, with a family member, or in an established residential program.

The Achieving Independence in Maine (AIM) Program

Given the current economic and social service landscape, providers and parents in the State of Maine came together in a grassroots effort in response to the limited services and supports for their children with intellectual disabilities and mental health diagnoses. Some family members had adult children who were struggling in the existing system of care. Others had children just transitioning to adulthood, and still others had children who were school age. The initial meeting took place in spring 2009 with representatives from 5 families, a local psychologist, educators, and Port Resources' Clinical and Administrative staff members.

The initial series of meetings identified a vision for working together. This group was specifically concerned about treatment/housing/support options for their children (some adult) with high functioning Autism and mental health diagnoses. All the youth were facing transition, or had transitioned, from public education and were floundering in existing systems of care. As the vision became clearer the group developed a residential program designed to "launch" youth into successful adulthood. The AIM group invited several community members to participate in an Advisory Board to guide this grass roots effort. Collaborative partners included: mental health providers, parent support groups, community housing agencies, university-based allied health educators, community case managers, vocational rehabilitation service providers, as well as representatives from key state agencies including the Developmental Disabilities Council, Department of Health and Human Services, and the Disability Rights Center.

The group met on an on-going basis, creating a model of service complete with vision/values/skills, all reflective of the current literature in the field (Raymond, 2009). The group named the program Achieving Independence in Maine (AIM). At

the same time, a number of parents and providers were meeting regularly with the Maine Coalition on Housing and Quality Services (Maine Parent Coalition, 2011). The focus of both groups was to develop creative options of care and support for their loved one with intellectual/developmental disabilities and mental health challenges. This led to a reconsideration of the current model of care in the state of Maine for adults with developmental and co-morbid disorders.

Current Status of Implementation of the AIM Program

With the Parent Coalition's completed narrative and plan, the decision was made to invite representatives from the Maine Department of Human Services to meet, with the goal of evaluating and identifying steps to the program implementation. The initial meeting between the Department and the parents took place in December, 2010.

The AIM advisory group continues to meet and Port Resources has developed a number of funding options including private pay and agency fund raising. They are also in early conversation with housing agencies and DHHS representatives. Professionals from Port Resources teamed with a faculty-student research team to pilot the implementation of the Social Cognition Interaction Training Program (Turner-Brown, Perry, Dichter, Bodfish, & Penn, 2008) originally developed and utilized by the University of North Carolina. This program was initiated to develop the social skills needed to live inter-dependently, work productively in the community, and establish friendships and positive relationships. This small therapeutic program and research study included both a group for young adults transitioning to adult roles and parent/caretakers. Results of this program will be evaluated using both quantitative and qualitative means.

In addition, a number of alternative and supportive living arrangements have been initiated in the community. One program is the William Street Project, a privately owned multi-unit residence, which in the fall of 2010 provided housing and supports to two individuals with developmental disabilities and mental health challenges. This was a public/private partnership between a family and DHHS.

Port Resources has dedicated three apartments in a centrally located apartment building in Portland, Maine. This will be the initial site of the AIM program. Two of the apartments are two bedrooms and the third is one bedroom. The AIM Program is intended to be staffed with direct

care staff 8 hours each day. The focus of the staff's work with the individuals will be skill building in the areas of activities of daily living, recreation/leisure, and developing and maintaining natural supports. In addition, there is a full time position dedicated to the individuals' vocational, recreational, social, and educational pursuits. Clinical services will be provided through our outpatient mental health clinic and can include individual therapy, psychological assessment/consultation, and psychiatric services, as necessary. In addition, a group therapy intervention program for social cognition and interaction training will be a component of treatment, since this is an area of challenge for youth with high functioning Autism. The program will not have overnight staff, but there will be an after-hours on-call to respond to emergencies. Administrative support/supervision to the AIM program will be provided by a Master's Level Clinician with significant experience with youth/young adults with ASD's. Through a partnership with the University of New England, AIM will have Social Work and Occupational Therapy Interns working on site. Program funding is likely to be managed differently for each individual. Some possible funding contributors could include the client/families, entitlement programs for utilities and food, grant/donation dollars, and the Department of Human Services. The cost of this program is significantly less than a community-based group home or residential services.

An Advisory Board comprised of Maine Parent Federation, Autism Society, Transition Network, University of New England Occupation Therapy Department, Vocational Rehabilitation, Community Housing of Maine, Maine Developmental Disabilities Council, Department of Human Services, parents and residents acts as a steering committee for program development and decision making. These collaborative partnerships serve as support, mentoring, and resource development. The AIM project is designed to launch young adults with ASD's into adulthood through focused attention on skill building, rehearsal and expanding natural community supports.

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