

A Guardian Ad Litem’s Guide to Placing People with Developmental Disabilities or Mental Illness in the Community

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People with developmental disabilities and people with mental illness present unique issues for Guardians ad Litem in Chapter 55 proceedings. The GAL’s role in assuring that individuals are not placed in overly restrictive settings is crucial. The GAL fulfills the role of advocate for the best interests of the ward and is often the gatekeeper to other sources of advocacy for the ward, most particularly adversary counsel and independent evaluations. Being an effective GAL requires an understanding of what is the “least restrictive environment” and the “most integrated setting” for these individuals. Transforming these concepts into actual placements requires an understanding of the various community resources and funding sources available to support them. This guide is meant to provide GALs with basic information in these critical areas.

Is there case law that a GAL should be aware of that relates to these issues?

Yes. In 2002 the Wisconsin Supreme Court held that counties are required to affirmatively show “a good faith, reasonable effort to find an appropriate placement and to secure funding to pay for an appropriate placement.” *In the Matter of the Guardianship of Judy K.*, 2002 WI 87, ¶28 (2002).

By placing the “find and fund” obligation on counties the Supreme Court clearly expects counties to seriously explore less restrictive alternatives for all protectively placed individuals before determining that their needs can only be met in institutions or other large facilities. It is reasonable to expect, therefore, that the comprehensive evaluation prepared by the county in anticipation of the *Watts* review (§55.06(10)(a) Wis. Stats.) would include specific information about: 1) what efforts have been made to evaluate the needs to be addressed in a less restrictive environment; 2) what efforts have been made to find providers able to provide the necessary services; 3) if no providers are immediately available, what efforts have been made to create a provider network or at least seek out a provider that could provide the needed services; 4) what specific funding sources have been examined to pay for any feasible non-institutional placement; and 5) the results of that examination.

In addition, the U.S. Supreme Court has held that unnecessary isolation and institutionalization of a person with a disability is unlawful discrimination under the Americans with Disabilities Act (ADA). *Olmstead v L.C.*, 527 U.S. 581, 19 S. Ct. 2176 (1999).

Under the ADA, “public entities,” including state and county governments, are required to administer their programs and services in the “most integrated setting” appropriate to the needs of an individual with a disability. 28 C.F.R. §35.130(d). In the ADA, “most integrated setting” is defined as “a setting that enables people with disabilities to interact with non-disabled persons to the fullest extent possible.” 28 C.F.R. pt. 35 App. A. pp. 525-526.

Understanding The Funding System

What are the basic public funding sources available to counties to place people with disabilities in the community?

The Medicaid program is the primary public source of funding for community placements, but there are other, state-funded programs also available, most notably Community Aids and the Community Options Program.

What parts of the Medicaid program fund community placements?

The principal parts of the Medicaid program that serve people with disabilities are the Medicaid “waiver” programs and the basic Medicaid card.

Medicaid “waiver” programs: Medicaid Waiver programs were created by the federal government as a means of allowing states to use federal Medicaid funds to serve people in their home communities rather than institutions. It should be noted that “waiver” programs are funded by “sum certain” appropriations, meaning that when funds are allocated people may be put on waiting lists for waiver services. Two “waiver” programs exclusively serve people with developmental disabilities. Three other waiver programs may serve people with developmental disabilities or mental illness.

Community Integration Program IA (CIP-IA): The CIP-IA program funds community services to persons who are relocated from the three State Centers for the Developmentally Disabled. Counties receive \$325 per day for each CIP-IA placement that occurs after July 1, 2003. If the cost of a placement exceeds that amount the county pays 40% of the excess cost. The remaining 60% of the excess cost is paid by Medicaid funds. § 46.275 Wis. Stats.

Community Integration Program IB (CIP-IB): The CIP-IB program funds community services to persons with developmental disabilities of any age who are relocated or diverted from nursing homes and Intermediate Care Facilities-Mental Retardation (ICFs-MR) other than the State Centers for the Developmentally Disabled. CIP I-B placements are funded at a base rate of \$41.86 (2004) per day. For “state-funded” CIP I-B placements the county pays 40% of the cost in excess of \$41.86; Medicaid pays the remaining 60%. For “locally funded” placements the county pays 40% of the entire cost of the placement; Medicaid pays the remaining 60%. §46.278 Wis. Stats.

Community Options Program-Waiver (COP-W) and Community Integration

Program II (CIP-II): COP-W and CIP-II are targeted at people over age 65 and people with physical disabilities. People with developmental disabilities or mental illness may be eligible for these waiver programs when they reach age 65 or if they also have a qualifying physical disability. §§46.27(11) and 46.277 Wis. Stats.

Brain Injury Waiver (BIW): The BIW serves a limited number of people with traumatic brain injuries who need significant supports in the community. People with developmental disabilities or mental illness may be eligible for the BIW if they also have a traumatic brain injury. §46.278, Wis. Stats.

Medicaid card services: The Medicaid card (which most protectively placed individuals are eligible for) covers a host of services that can be used to support people in community placements, including personal care services, home health care and durable medical equipment. §49.46(2) Wis. Stats. Medicaid card services are funded entirely through the Medicaid program. As a general rule, no county dollars are involved. Medicaid card services are funded by “sum sufficient” appropriations, meaning that the services are paid for without regard to the number of people requesting them. Federal Medicaid law requires that Medicaid card services be provided with “reasonable promptness,” effectively making it illegal to have waiting lists that exceed 90 days.

“Money Follows The Person” Initiative: Beginning in 2005, counties will be permitted to use Medicaid dollars that had previously been earmarked solely for institutional care of persons with developmental disabilities, to support community placements. Traditionally, if a person in an institution could be served in the community, a county would have to use scarce CIP, COP and Community Aids resources to fund the placement. By contrast, the institutional placement was supported entirely by Medicaid card service dollars. Under this new initiative, counties will be able to use the state funds that paid for the institutional placement to pay for the community placement. In a real sense the “money follows the person” from the institution to the community. Under this initiative, counties will also be required to pay 40% of the cost of the institutional placement, effectively eliminating the institutional bias in the funding system. §49.45(30m) Wis. Stats.; WI Act 33 §§1383-1388.

What are “Community Aids” and the “Community Options Program”?

Community Options Program (COP). The Community Options Program is an entirely state-funded, county-operated program which pays for community-based services to Wisconsin citizens who need long term assistance with performing the activities of daily living. It is sometimes called “regular COP” or “COP Classic” to distinguish it from COP-W. COP is designed to divert or relocate individuals from nursing homes or other institutions. The target populations include people who are elderly (age 65 and older), have developmental disabilities, physical disabilities, serious and persistent mental illness and/or chemical dependencies who require a level of care for which Medicaid would pay for institutional care. COP is not, however, part of the Medicaid program. Because COP is not part of Medicaid, it can pay for services that the “waiver” programs cannot. §46.27 Wis. Stats.

Community Aids. Each county receives funding from the state to support its services to people with developmental disabilities, mental illness and substance abuse. Community Aids is allocated on an annual basis and is distributed in a single payment to each county. Counties are required to match these funds (9% match requirement) and many counties provide a substantial amount of “overmatch” dollars. Like COP, Community Aids is not part of Medicaid. It can therefore also pay for services that the “waiver” programs cannot. §51.423 Wis. Stats.

What are the public funding sources for people with Mental Illness?

The Medicaid Card, COP and Community Aids are the principal public funding sources for people with mental illness who are protectively placed. There is no Medicaid waiver program targeted at people with mental illness. However, people with mental illness who are age 65 and older or who have another qualifying disability may be eligible for any of the waiver programs discussed above.

Community services covered by the Medicaid card include targeted case management, crisis intervention, community support programs (CSP), coordinated community services (CCS), prescription drugs, day treatment, and outpatient psychotherapy. Community Aids and COP can be used to fill in parts of an individual service plan that are not covered by Medicaid. Community Aids is also the sole public funding source for people with mental illness who are not eligible for Medicaid or COP.

For targeted case management, crisis intervention, CSP and CCS the county pays 40% of the Medicaid cost, even though these services are Medicaid card services.

What other sources of support exist?

The Division of Vocational Rehabilitation is another source of public funding that can be used for the purchase of needed adaptive equipment and some vocational services. In addition to public funding sources, a wide variety of potential private sources exist that could support community placements. Many of these sources are disability specific. County case managers should be familiar with these sources and use them when possible. Finally, informal community-based supports should be explored and utilized. These include involvement of family and friends in the service plan for the individual. These sources of support may or may not cost anything and greatly contribute to the integration of the person into the community.

What are the basic standards associated with all protective placements?

Under Chapter 55 courts are required to place people in “the least restrictive environment consistent with the needs of the person to be placed and the placement resources of the [county.]” Under *Watts v. Combined Community Services*, 122 Wis. 2d 65 (1985), protectively placed individuals are entitled to an annual court review of their placement. As part of that review a GAL is required to be appointed. GALs are required to make a recommendation

to the court regarding whether the current placement is the least restrictive placement consistent with the individual's needs. The GAL is required to seek an independent evaluation of the individual if that appears necessary. *Watts* at 84-85.

New Statutory Requirements That Apply Only To People With Developmental Disabilities

In the 2003-2005 budget act the legislature added several provisions to Chapter 55 and related statutes that apply only to individuals with developmental disabilities who are either in, or are being considered for placement in, private or county owned "intermediate care facilities for the mentally retarded (ICFs-MR)" or "skilled nursing facilities (SNFs)". The changes do not apply to people protectively placed in any of the three state centers for the developmentally disabled.

What were the changes to Chapter 55?

Several amendments and additions to Chapter 55 were made. Most significant is a requirement that people with developmental disabilities who are either in, or being considered for placement in, institutions be placed in a community setting unless there is a specific finding by the court that a private or county-owned ICF-MR or SNF is the "most integrated setting" appropriate to the needs of the person. §55.06(9)(a), WI Act 33 §1510.

What does the term "most integrated setting" mean?

"Most integrated setting" is defined as "a setting that enables an individual to interact with persons without disabilities to the fullest extent possible." §46.279(1)(bm). WI Act 33 §1132. It should be noted that although this new state statutory definition of "most integrated setting" applies only to people with developmental disabilities who are either in, or being considered for placement in, institutions, the "most integrated setting" requirement of the ADA (from which the state definition derives) applies to all people with disabilities.

How will a court know what is the "most integrated setting" for a given individual?

Counties are required to create plans for providing home or community-based care in a noninstitutional community setting. §46.279(4); WI Act 33 §1132. In initial protective placement proceedings counties are required to provide a statement or testimony regarding whether the individual could be served in a noninstitutional setting. §55.06(8); WI Act 33 §1509. In *Watts* reviews the county is required to provide a copy of the plan to the court and to the guardian. §55.06(10)(a)2.; WI Act 33 §1514.

Are there timelines imposed on counties for preparing the "most integrated setting" information to courts?

Yes. Generally, counties have 120 days to prepare the plan. When that 120 days begins depends on what type of proceeding is involved. In *Watts* reviews the 120 days begins 120

days before the *Watts* hearing is scheduled to occur. §§55.06(10)(a)2. and 46.279(4)(d); WI Act 33 §§1514 and 1132, respectively. This assures that the information will be in the hands of the court and guardian at the time review occurs. For initial placements in ICFs-MR the 120 days begins 5 days after the individual applies for admission to an institution.

The Importance of “Most Integrated Setting”

What does “most integrated setting” mean in practical terms and does it differ from “least restrictive environment?”

Both “most integrated setting” and “least restrictive environment” mean much more than a decision between a locked or unlocked unit. The goal should be to enable people with disabilities to spend most of each day and most of their lives in positive relationships with non-disabled people in typical community settings. The focus is not on the type of facility, but rather the provision of necessary services and supports a person with disabilities needs to have life experiences most community members desire for themselves. The specific integration mandate of “most integrated setting” makes explicit what was always implicit in “least restrictive environment.” Because the ADA applies to all protective placements the concept of “most integrated setting” also applies to all protective placements.

Why is most integrated setting important?

Historically, people with disabilities, especially those with severe disabilities, have been placed in institutions as a result of stereotypical negative assumptions about who can and cannot live in the community. The expectation was that people described as “profoundly retarded” or totally dependent on others would be endangered by the everyday challenges of community life and therefore must be protected from potential risks. There was a prevailing pessimistic view that people with disabilities could not grow or adapt to life outside the “security” of an institution.

We have now learned that through individualized planning and arranging of services and supports people with complex physical, medical, psychiatric and cognitive disabilities are successfully living in the community. People who have lived most of their lives in institutions can and do adapt and actually flourish in small community homes with the appropriate services and supports. In fact, we are learning that by providing people with individualized supports in the appropriate environment (fewer people, home modifications, well trained staff, etc.) the frequency and intensity of “challenging behaviors” diminish and often disappear over time.

In the mental health system the concept of recovery has been adopted as the guiding principle. This means that persons with severe mental illness can have full and productive lives in the community if they receive services or supports that they want and need.

How can community services be arranged to create the most integrated setting?

The practice of congregating people with disabilities has had several negative consequences, including lack of personal attention, regimentation and little attention to adaptive skills. People described as having challenging behaviors often develop, maintain or increase those behaviors as a means of coping with the stress of the institutional setting. More recently, county human services staff and service providers have been looking beyond a person's diagnostic labels when planning community services. This approach is frequently referred to as "person-centered planning." The intent is to learn as much as possible about the person; their likes and dislikes, the most important things in their life, their medical, physical and emotional needs, etc. We have learned that this is the most effective approach to planning services, regardless of the severity of the person's disabilities.

Based on a person-centered plan, informed decisions can be made with the guardian as to the services and supports that will be necessary to provide the most integrated setting while ensuring the person's health and safety. The plan will help provide the answers to questions such as: What does the person want in terms of services and supports? What should the home environment look like? Does the home need to be accessible? Does the home need to be modified to accommodate behavioral difficulties? Does the person need 1:1 assistance and supervision? What training do staff need? How many staff need to be available to ensure the person has frequent opportunities for community activities? What medical or mental health services need to be arranged? What should the person be doing during the day? The goal is to build community services and supports around the person rather than fitting the person in a certain type of building.

Can an ICF-MR or other institution be the "most integrated setting"?

Theoretically, yes. However, given the availability of very sophisticated community services it is unlikely that it would be. A person most likely to require institutional care would be a person with an extremely fragile medical condition in addition to a developmental disability or mental illness.

What are the GAL's responsibilities?

Under *Watts*, one of the primary duties of the GAL is to make a recommendation as to whether the ward's current placement is the "least restrictive setting." A GAL cannot make such a recommendation in a vacuum. Therefore, a GAL's responsibility is to spend time trying to develop an understanding of who the person is by learning about the current placement and reviewing in detail the information provided to the GAL and the court. The county is obligated to look beyond the person's current placement to describe what services and supports could be provided in the community to meet the person's needs. Given the recent changes to Chapter 55, this obligation is heightened with respect to people with developmental disabilities who are in, or being considered for placement in, institutions. If the person is in a restrictive setting and the county is recommending no change in placement, it would be appropriate for the GAL to request an independent assessment which includes a description of possible alternative community options.

How does the guardian's opinion fit into this process?

The GAL is charged with representing the ward's best interests. That means making sure there is accurate and comprehensive information about placement options in the court record to ensure an appropriate placement decision is made, even if the guardian is opposed to a change. If the assessment process is done properly, the guardian will be directly involved in describing the services and supports the person needs to live in the most integrated setting.

Often guardians may be resistant to change because they are unaware of the community options that are now available. With the down-sizing of institutions, we have found that guardians who previously opposed community placement became supportive of those placements after observing the positive changes in their wards' lives following the move to the community.

What are some other resources available to GALs?

Staff members of the Wisconsin Coalition for Advocacy (WCA) are available to provide case consultation and technical assistance to any GAL of a person with a disability. In addition, the State Bar of Wisconsin publishes the "Guardian ad Litem Handbook," an exhaustive treatise on all matters relating to the GAL's role in guardianship and protective placements. WCA publishes "Rights and Reality," a comprehensive overview of legal issues affecting people with disabilities.

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