A myth is an imaginary story that lives in the minds of people that tell it, working as a set of instructions for how things are or should be. In the case of the story, "Some People Really Need an Institution," if we sift facts from fiction we can see that the story works to perpetuate a myth.

The fact is there are people who have significant health issues that are complex, need a trained eye to evaluate, require specialized intervention, are sometimes chronic, and sometimes critical. The fiction is the leap to the conclusion that they need a special kind of building to live in and to share with others with similarly complex needs.

Let’s critique this leap. There is readily available evidence to refute the conclusion. For every person for whom an institution is suggested, there is a “functional twin” with exactly the same needs who lives successfully in a home in a community.

However, functional twin evidence is not enough (apparently) to sway those who skeptically pose the question. Their worry is not eased by such evidence but, rather, is built on beliefs fueled by imagination. Dispelling the myth requires confronting that imagination and unbundling its elements to find our way from the imagined to the actual and, ultimately, to a different imaginable conclusion.

When the myth is raised around health care issues, it usually references notably fragile conditions, complex technologies or medical interventions. The list seems daunting and evokes the feeling that surely “These People” are the ones for whom institutions are necessary.

The other side of the coin details attributes of institutions. This description usually highlights professional credentials. The credentials seem as impressive as the conditions are daunting, and evoke the inference that maybe “These People” need those people and their expertise.

Hence, the Leap is made. “A” needs “B,” therefore A should live where B is. It is at this juncture that we can further expose the errors in logic. We can ask the question differently. Rather than asking “Doesn’t A have to live where B is available?” we can instead ask, “Can B be available where A lives?” Posing the question differently is much more than an argument to expose illogic; it is a methodology to work through. Sometimes this reversal and its serious exploration can result in a person having the opportunity to live in his/her community rather than being forced into an institutional setting (though sometimes not, an issue I will come back to).

First, we need to push deeper to get to the bottom of imagination that fosters the Leap. Whether the proposed institution is a hospital, nursing home, mental retardation facility, or group home, “special” places for “special” people are really nothing more than two elements:

1. The physical environment
2. The people involved

Let’s look at each more closely.

1. The physical environment. Any residential setting is a set of rooms in a building with walls and ceilings and hallways. Some of the rooms have particular features. Some have cooking equipment, some have medical equipment (e.g., oxygen), some are configured to separate people from each other (e.g., isolation for infection control), some are configured to have people congregate (e.g., day rooms, dining rooms, lounge rooms).

If we look at any single individual, it is hard to conclude that this Person needs cafeteria dining arrangements; or this Person needs to share a residence with 5, 25, or 360 other people; or this Person needs a roommate with equally complex needs.

When we closely examine what this Person does need, we find it is oxygen, not the fact that is piped in from a line in the wall; or medications, not the fact that they are stored in the pharmacy downstairs or nursing, not the fact that they park in the employees lot. Ironically, we might find it is the fact that this Person needs to be protected from contagion from other residents that necessitates the isolation room he “needs.” On close examination, the physical space does not offer something that cannot be replicated (or improved on) in another building with fewer rooms and fewer roommates. Something like, say, the size and scale of a family home.

What this Person does need, however, is other people and their expertise. This takes us to the
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second element of any residential arrangement, that is, the configuration of people and their activities within the physical building space.

2. The peopled environment. Any residential facility is a set of people. Often a critical issue for individuals with complex medical needs is access to the expertise of people. The peopled environment boils down to logistics and numbers, that is, people with time, energy, expertise, and availability.

Let's look more closely at the peopled environment needed by individuals with significant disabilities or complex medical needs. An argument often made for institutional care is that there is a physician available. But where is that actually true? It is true in an acute care hospital. It is not true in most nursing homes, mental retardation facility medical units, or specialized group homes.

Usually a physician is available only on some days or some shifts or is "on-call" for phone-in intervention rather than a face-to-face contact. In the rare setting where a physician is actually present 24 hours a day, 7 days a week, we can examine how many hours of that 24 hour period the physician spends with This Person. The answer will be measured in minutes, not hours.

The credential most often referenced for people with complex medical needs is a nursing license. An argument often made for institutional care is that there is a nurse (or nurses) available 24 hours a day, 7 days a week.

Again, we can examine how many hours of the 24-hour day the nurse actually spends with This Person. In many specialized settings, it is not a nurse who provides most care but, rather, an aide with a modest amount of training. If there is a nurse available, he is passing medications, adjusting equipment, observing, or intervening for particular kinds of care for short periods of a 24-hour day.

For very few individuals does a nurse provide the bulk of the direct care. And for those individuals, the nurse could apply his expertise in other buildings, like those of the size and scale of a family home. Or alternatively, the nurse may be able to delegate to a regularly available parent or other family member certain care which he would not delegate to a roster of interchangeable staff of a facility.

What we find when we break down the peopled environment is that the need for institutional care is not located in This Person, but is located in the way we've organized needed assistance into a limited number of settings. We find That Person does not need an institution but, rather, we have configured the delivery of services so that the only place that offers people with the needed time, energy, expertise, and proximity are congregated in a building that is not the person's home. These logistics are alterable.

Without a doubt, logistics are no small feat. Getting enough people with time, energy, and expertise into the homes of people who need them is a managerial challenge. Sometimes it is successfully met and, unfortunately, sometimes it is not.

If we frame the problem as located within the individual, then we stop short of finding answers because the individual's characteristics may not be modifiable. If we frame the problem as logistical, we can find logistical answers to create home life because logistics are modifiable. We need to shift our thinking to see that the problem doesn't lie within the person with the complex medical issues — it lies in the arrangement of our services configuration.

So the question, "Do some people need institutional care?" can be reframed as, "Have we organized our care arrangements in such a way as to provide them in a person's home?" When push comes to shove, these decisions are less about what individuals need and are more often about economics.

Defense of institutions invokes "economy of scale" arguments that say we need to put individuals with like needs together in physical spaces to be able to afford the caregivers that are needed. This argument reveals that it's not that individuals need institutions, but that institutions need multiple residents to share the helper-people in order to make the economics work. If we can't figure out how to reconfigure the service arrangements, let's at least stop saying people need institutions — let's say institutions need people.

Of course, to reduce the problem to logistics is too simplistic. It will not resonate with skeptics that all we have to do is manipulate staffing schedules. In truth, a much bigger task to tackle is the imagination. It's not the intellectual exercise of reason but the emotional exercise of imagery and imagination that stymies our efforts.

In this issue of TASH Connections, you will read about states, agencies, and individuals who have worked out better ways to organize their physical and peopled environments. You will find examples of policies, practices, and funding, but what it looks like on-the-ground is the imaginable that most sparks change.

For many years I have worked to help children growing up in nursing homes to find their way to family homes. To be sure, changing the pathway from residential care to family homes requires policy and funding changes. It also requires systematically tackling each and every child and family on their own terms and figuring out arrangements that work. These arrangements vary from schedule modifications to home modifications, from on-call systems to ambulance arrangements, from back-up generators to back-up nurses, from willing-able to willing-able alternate families.

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Along the way we met kids with complex needs like Tiffany. Born with a rare syndrome, she needed a tracheostomy and ventilator to breathe, a tube in her stomach for nourishment, a wheelchair for mobility, and caregivers who knew how to judge her breathing, adjust her vent settings, do her tube feedings, suction her airway, and position her in her seating equipment. Her birth family was too frightened of the equipment and the imagined difficulty of learning to care for her at home. They were unwilling to have strangers intrude on their home to do it for them. Another family in their community was willing.

We helped the birth family to make the loving decision to enable their daughter to enjoy the important need of childhood for a safe, secure environment that includes at least one stable, predictable, comforting, and protective relationship with an adult, not necessarily a biological parent, who has made a long-term, personal commitment to the child’s daily welfare and who has the means, time, and personal qualities needed to carry it out” (Greenspan 1997).

In every institution, we found children like Tiffany—with the kind of needs that scare a lot of us. We also found people like Luis, whose condition was equally intimidating to a lot of us. Luis had been in a coma for two years due to injuries from a car accident. A coma conjures up images of being so medically fragile that surely an institution is required. A careful examination of Luis’ care revealed he needed positioning and skin care, tube feeding and trach care. His family had overcome their imagination of that kind of care and become very skilled, with the nurse’s blessing, at providing it on their daily visits.

What kept Luis in a nursing home was not his coma/condition, but the fact that his family home and car were not accessible. These logistical challenges were surmountable. By arranging housing, transportation and a nurse to make several home visits a week and be available by phone, the family was able to take Luis home. When we rearranged the people he needed, we found there was nothing about the nursing home that Luis required. It had only helped “efficiently” arrange his care.

Neither Luis or Tiffany needed the nursing home. What they really needed was the love with people who loved them and had enough support to thrive as a family. I am not saying that solutions are readily available; I am saying they are feasible. It took a year to get Luis home, and funding to get Tiffany a family, but asking “What will it take” raises more surmountable problems than asking “Don’t those people need that place?”

Some of the mythology about people whose needs are “too” severe arises from letting our imagination go unchallenged. The imagined “too”-ness can be dissolved by unpacking its underlying details and shifting to imagining what it would take.

If we look at a minute-by-minute analysis of what the care in most “special” settings really consists of, we can replicate it (or improve on it). We can pull back the curtain and see it is only people in buildings. Once you look at the actual details, they can be broken down into “who” rather than “where” in a process that allows an alternative to become imaginable and, ultimately, doable.

The good news is that methodically unbundling logistics can sometimes, in and of itself, address the most feared aspects of our imagination. The very process of examining the logistics can dispel the imagery and break down the imagined difficulties. This is as true (often more true) for us planners as it is for individuals and their families or loved ones. The logistics can be confronted as challenging but (re)arrangeable given enough ingenuity and a committed group of “co-conspirators.”

The bad news is that too often the problem isn’t the theoretical feasibility of (re)arranging the peopleed environment or finding funding, but the trustworthiness of the arrangements. We find competent parental caregivers in a family home who aren’t scared about the care; they’re afraid about what will happen to their loved one if something happens to them. And the something that might happen imminently is the caregiver dropping from exhaustion. They either have not had people-help—the kind with energy, time, and expertise—or the promised help didn’t show up, or weren’t on-call when called, or weren’t as expert as their credentials suggested. As unfortunate as this is, it is no less true in facilities that struggle with turnover, no-shows, and too few staff across too many residents.

In truth, we don’t find flimsy arrangements for families compared to quality facilities but, rather, flimsy arrangements for facilities, as well. If we are going to spend the money and work out the logistics to adequately support facilities, we might as well go back to the drawing board and work out arrangements to support people in their own homes.

But the myth that prevents the work is stubborn. I was recently talking to an attorney who serves as the guardian for a young man living in a nursing home who was paralyzed and uses a ventilator following an accident. After meeting him and learning about what he needed, she imagined him living in a home in the community (albeit with complex accommodations). Even as she fought for home-life for him, she asked me the mythical question, “But aren’t there some people who really need an institution?” She didn’t say it in a way that made it sound like a question, but rather as an assumed answer. She hadn’t yet met Those People and hadn’t yet worked through the details of what they needed, like she had with the young man she was supporting. She let her unchallenged imagination assume such imaginary people.

If we confront our fictional imagination and dissect the actual facts, we can find our way to answering the mythologized question, “Nope.”

Reference
provider (either a developmental home provider or family member).

Judgment is Critical in Making Care Decisions

Fifth, and perhaps most important of all, the team members must be trained to use conservative judgment in all matters relating to a person's medical care. Any question or concern that a provider has must be followed up immediately. It is not appropriate in these cases to delay these actions in order to see if an emerging concern worsens or resolves. In this regard, these placements must be directly linked to the credentialed medical community in order for prompt and appropriate assessment and treatment to occur at any hour of the day or night.

The advantages of a community-based program have been well defined elsewhere. It has been our experience in Vermont that people with very complex medical needs can be supported successfully and safely within the same basic types of program models as are people without such needs.

There is a difference in emphasis when setting up the person's support team relating to the types of individuals who must be on the team. The nature of training and support for the principle care providers, and for the types of monitoring that need to be in place in order for these placements to succeed over time must be well thought out. With this care, it has been possible for the Vermont system to support even the most medically complex individuals outside of an institution.

Meeting the needs of a person who has complicated medical needs within the framework of a community-based program can be very stressful. In addition, many of these individuals require medical care continuously throughout the day. In Vermont, through the Medicaid Waiver program, individual support budgets have at times been designed to enable additional resources (e.g., staff or respite support) to be brought into the home environment in order to assist in the provision of needed special care procedures.

These resources may be regularly present within the home, or may be accessed during times when the medical needs of the individual are most acute. In either case, all of the people called upon to meet these needs are trained in the special care procedures by properly credentialed medical professionals, and ongoing monitoring and support is provided.

Summary

Providing community-based services for people who have complex medical needs can be difficult. However, designing and supporting these types of services within the context of a community-based system of care is well within the capabilities of such systems. The steps outlined above are essentially the same steps taken in supporting someone without complex medical needs. The differences lie in the extent to which specialized training and support services must be made available and maintained in order to assure that the individual has proper medical assessment, care, and oversight.

In organizing the support team, generically available community medical resources are brought into the team process. At times, these supports can be accessed through the individual's Medicaid card; at other times, they can not. In these circumstances the individual's support budget, which is developed through Vermont's Home and Community Based Waiver program, must include the additional capacity to assure the ongoing involvement of essential medical professionals within the team process. Even in rural areas of Vermont, we have found it possible to locate properly credentialed and motivated medical professionals to participate as members of these teams.

Nothing in the program development process is intended to separate or isolate the individual with complex medical needs from the medical resources located within most communities. People served within Vermont programs who have extreme medical challenges access their physicians with appropriate frequency and, when the need arises, they access other medical facilities, including hospitals. Rather than limiting treatment options, the dynamic team approach that is followed helps insure proactive responses to the changing medical needs of this unique population. As a result of this approach to service delivery, the community agencies in Vermont have been able to include the vast majority of people who have extremely complex medical needs within typical community programs and services.

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