

# Out of the Institution Trap

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## Summary

The institution is a trap for people. Just getting out of the institution doesn't mean getting out of the trap. People with disabilities can be kept apart from other people, treated as if they were less valuable than other people, and controlled by staff even in an ordinary house.

It does not have to be this way. People with disabilities and their allies have learned how to assist people to make choices, make valuable contributions, and participate in community life. To learn how to do these things people have to get out of the ways of being with each other and thinking about each other that keep them in the institution trap.

We have read about Tom Allen in each section of this book. Many bad things were done to Tom in the big and small institutions he lived in. He fought back and took as much freedom as he could, no matter how hard the institution tried to own his life. Tom's story shows us ten ways to fight the institution trap.

- Reach out and make friends.
- Remember the people who have loved you. Remember their love even if they have also let you down or hurt you.
- You can find spaces to be free if you learn all about how the institution controls people.
- Find safe ways to use your voice. Don't give up when others don't listen.
- Be a decision maker.
- Learn to do whatever you can for yourself, even if it is hard and takes a long time.
- Make a positive difference to other people with disabilities.
- Don't think like the institution. The institution wins when you give up and believe that you are no more than the institution thinks you are.
- Tell and re-tell your own life story to anyone you can trust to listen.
- Keep your dream alive and guard it from people who try to kill it.

Lobster pots are designed to catch lobsters. A man entering a man-sized lobster pot would become suspicious of the narrowing tunnel, he would shrink from the drop at the end; and if he fell in, he would recognize the entrance as a possible exit and climb out again.

A trap is a trap only for creatures which cannot solve the problems that it sets. Human-traps are dangerous only in relation to the limitations on what humans can see and value and do. A trap is a function of the nature of the trapped.

–Geoffrey Vickers (1970, p. 15)

### **The Institution Trap is Crafty**

As lobster pots are to lobsters, institutions for people with intellectual disabilities are to us humans: deeply dangerous and revealing. Energized by our collective uneasiness with imperfection, dependence, and mortality, institutions trap us. We mindlessly impose segregation and supervision on people who require accommodation and assistance due to impairments in learning, communicating, or moving --treating them as if they were devalued or dangerous or disgusting Others (Nussbaum, 2004). That we apply the cosmetics of cure, care, or choice only makes the trap more alluring, keeping ordinary members of the public at a distance, detachedly admiring the work of those so busy with assessments and activities and treatments that the entangling mesh escapes notice.

The institution trap is protean. When it can no longer ensnare large numbers in a collection of buildings crowned by a water tower, it shifts its shape and assumes the disguise of an ordinary-looking house. Maria (Chapter 19) makes her life with four other women whose tendency to wander is managed by staff who lock the doors rather than imagining and practicing a life with their charges that might be more engaging than playing endless games of containment and escape. Such imagination and practice would be informed by positive approaches to dealing with troubling behavior (Lovett, 1996), but such interventions cannot work apart from an organizational culture that encourages staff to recognize and delight in a sense of common humanity. Such a sense allows staff to

discard the mask of impersonal overseer. Apparently caught among staff lacking this vital imagination and skill, Maria remains suspended in the institution trap, her situation recounted here only as a commentary on the reproduction of nineteenth century patterns in twenty-first century places.

For those concerned more with offering people a good life than with supervising their maladaptive behaviors, it is possible to backtrack from even a big mistake and find a way to slip through the institution trap. Hacki (Chapter 20) finds his familiar broken chair in an institution ward superior to being placed in a five-person group home. He reverses this decision when fellow Maori invite him to take a seat among the elders. Themselves taking a stand for the value of their culture by creating a Maori service for Maori with disabilities, these staff join Haki in escaping the institution trap. They respect the dignity of his age, reunite him with his *fanau* (extended family), and live in ways intended to heal his Maori spirit. This second chance is the product of personal relationships between people who value their shared identity as Maori, an organization dedicated to asserting the specific contribution that Maori culture can make in a service world dominated by European values, and a political climate shaped by the assertion of both Maori rights and disability rights.

The institution trap is systemic. Arthur (Chapter 21) died painfully and unnecessarily from scalding. His fatal injury was not sustained in a large public institution, but in a community home, whose operators ineptly tried to cover-up the cause of death, maybe to protect their trading position. The state's pathologist and the coroner assigned no fault in the death of this person, described in their record as a "low grade Mongol." Arthur's move from the institution into a lethally incompetent situation lacked the safeguard of any authoritative way to review the facility's competencies and comforts from Arthur's perspective. Instead, his placement was driven by a political priority that ignored his interests: the erection of a contract-based market in community care dominated by private entrepreneurs and fed by the closure of publicly operated institutions. People can have more security, even within the constraints of a system designed to offer contractors advantageous business conditions (Cambridge, 1999), but such safeguards take thoughtful design and painstaking implementation.

The institution trap is crafty. Some people with mild intellectual impairments, like Clæs (Chapter 18), have escaped disability-service enforced segregation, but not a form of social isolation that greatly increases the risk of addiction and anti-social behavior. In an earlier generation, Clæs might have found himself preventatively detained, living as a “worker-boy” in an institution for the mentally retarded. Today the prison system does the work of institutionalization as Clæs joins too many other unsupported, isolated people with mild intellectual disabilities in jail. As those who created “Meeting Place No 10” know, it is possible to generate positive ways to confront social isolation and devaluation, but this effort has come too late for Clæs. Other people, like Jason (Chapter 19), are entangled in a net woven of ineffective responses to what could be a compulsion to abuse children. The accumulation of difficulties and support failures led the intellectual disabilities service system to export him: first into the prison system, and then into indefinite detention in a secure mental health facility under the authority of a public guardian. It is not necessary that the institution trap claim Jason. There are forms of assistance emerging that protect other citizens while assisting a person to live a life that makes sense. However, even limited success requires a depth of knowledge and wisdom that can only be acquired by service workers who are willing to recognize humanity in people who do truly scary and sometimes bad things and who are willing to learn how to mindfully surround opportunities for growth with protection (O’Brien, et al., 2003).

### **Resisting the Institution Trap from Inside**

Fans of *Star Trek: The Next Generation*, have met The Borg, a cybernetic life-form whose mission is to improve the quality of life for all those they meet by assimilating them, discarding their cultures and identities, and amalgamating them into an efficient machinelike collective. Their monolithic spacecraft harnesses great technological power to enforce their typical; greeting to strangers, “You will be assimilated.” To those who object to assimilation, they matter-of-factly respond, “Resistance is futile.” Of course, in *Star Trek*, as in life, the interesting stories unfold through the actions of those who believe that resistance is possible, even if risky and often less than fully successful. The institution trap is implacable and its impersonal technologies can strip away people’s

humanity, but, like The Borg, its power multiplies when people buy the story that resistance is futile.

*Learning to see resistance*

Fixating on wounds caused by the cogs of the institution trap can obscure the agency and creativity of those caught in its gears. It can be tempting to cast institution inmates as simply passive victims, waiting, as inert as Snow White, for a rescuer to appear.

Alternatives and advocacy are surely necessary to get people out of institutions, but a more nuanced view is available to those who practice seeing the ways institutionalized people carve moments of meaning and freedom out of the asylum's constraints.

Understanding how to see and encourage these capacities for resistance is critical to moving beyond the institution trap.

Bob Williams (2004) --poet, alternative communication user, disabled policy analyst and activist, and Clinton Administration US Deputy Assistant Secretary for Disability, Aging and Long Term Care Policy-- demonstrates the appreciative, open and unhurried gaze necessary to recognize "the subtleties of the moment" that reveal how two institutionalized people "knowing that they're all they have ...learn to make do."

Dick and Jane

They've shared the same mat since they were children,  
lately though the staff has been setting them down  
so that they're facing in opposite directions of one another,  
probably to avoid any funny stuff.

It doesn't matter that much though;  
they'll nestle together no matter what,  
knowing that they're all they have,  
they learn to make do.

Her body is that of a child  
though her face is taking on the features of a beautiful young woman;  
looking into her hazel eyes, I'm almost mesmerized by their sparkle,

it took me a while to figure out the score.

Finding pleasure in giving her lover a back rub  
with spasmodic strokes of her arm, she massages the small of his back;  
smiling, he responds in kind by running his whiskers through her toes,  
she gives out a slight laugh;  
they move an inch or two closer to each other  
hoping that the staff doesn't pick up on the subtleties of the moment;  
they don't of course.

*Remembering the danger*

Though resistance is possible, it is often dangerous. Tom Allen (Chapter 1) was “put in a corner, facing the wall, for hours on end simply for talking out of line.” Other inmates saw him and learned. The institution trap can close very tightly indeed around those who resist openly. As Bob Williams shows (2004), violence against resisters can be cloaked as therapy. Others saw what happened to Johnny and learned.

The Marathon Man

Johnny ran.  
that was his problem,  
he was what the staff called a runner  
logical since he ran whenever he could  
  
one minute  
they thought they had him  
three ways to sunday  
tied to the bedpost  
    with someone else's soiled sheets;  
  
then they'd no sooner turn around  
and he'd be up to his hary houdini  
routine all over again.

even the aides admitted he was pretty  
smart for being a retard;  
all the rest of them would sit and rock.  
  
but not Johnny  
he'd jump up  
dart this way and that.  
  
then the next thing you know  
he'd find an open door  
or leap through a window  
  
and he'd be clocking the mile  
on the institution's main drag  
at three-point-ninety-two  
like the long distant runner he longed to be.  
  
they tried vinegar spray,  
four-point restraints,  
even leaden shoes.  
  
nothing slowed his free stride  
until they placed electrodes on his hide  
and shocked him.  
  
shocked him silly.  
  
now he's on the back ward  
rocking to and fro  
to and fro  
to and fro...

*Learning to make do*

Tom Allen learned to make do in very constrained circumstances. By passing on the gift of Tom's autobiography (Chapters 1, 7, 12, and 17), the editors of this book honor one of the projects that brought meaning to his life: teaching lessons in how people should not

be treated and how those subjected to such treatment can assert their freedom despite an impoverished, isolated, controlling environment. They also provide a catalog of the ways the institution trap works and how to resist it.

Being caught in the institution trap brought Tom many troubles. The Epilogue says that he suffered much more than he wrote, but he wrote about troubles enough. The next few paragraphs detail the workings of the institution trap on Tom. Abstracting these insults to Tom's humanity yields a list so cold as to be false to Tom's mostly gentle, hopeful way of telling his story. In his telling, the warmth of his generosity and hopefulness balances the coldness of the treatment that tempts him to bitter anger and despair. However, the chill of enumerating some of what Tom endured gives proper proportion to the acts of resistance Tom authored.

Tom was taken away from his family twice by a system with no capacity to support his family to raise him. The doctor in the institution specialized for his care sent Tom home to die when he was six years old.

Tom recounts four years of troubles after re-admission at age 16. His desire to make some of his own decisions kept him in trouble with staff. He was not allowed to bring his belongings from home (and did not have any personal belongings for another 32 years). He wore hospital clothes. "No school. No work. No physical therapy. No speech therapy. No nothing." Throughout his long stay in this facility, dental work meant extractions but no fillings or dentures, a practice that made it harder and harder for him to eat as the years went by. Though he had occasional letters, he had no visitors for five years. His anger at abandonment grew, and he began to question whether even God was still with him. "My desperation was so deep it is hard to describe."

Anger and desperation led him into bigger trouble with staff, which resulted in demotion to ward to live in poorer material conditions with more severely disabled people. Tom shifted his survival strategy and turned what was intended as punishment into roles meaningful to him as a helper, mediator, and organizer –roles which he continued to play for the many of the next 37 years. Moving to an institution closer to his family led to the loss of these roles. "I just sat around all day and was terribly bored."

At age 69, Tom had his own room for the first time in his life –this lasted for about a month before he moved to another institution in order to improve his chances of finally moving into a group home. In this facility, for the first time in his life, he lived on a ward and had meals at a table that included women. While this facility offered some new opportunities, it also posed new threats. Tom was repeatedly victimized by other residents and lived in fear that he could not defend himself and that staff would not protect him. His glasses were broken repeatedly. Money and clothing was stolen from him. Food was taken from him and thrown at him. He withdrew into his room for self-protection. But, for Tom, there was something worse than physical victimization and restrictions on his movement, as he proclaims in his petition for an injunction to provide him a community placement.

I have been frequently disappointed by the state's broken promise to find a home in the community for me. This has been the worst indignity and disappointment I have suffered.

...I am often depressed; I worry about whether I will ever live in the community before I die.

After two and a half years of hard work, Tom moved into a community residence with three other people, returning to the institution to spend his days for two years and then, after “retirement” sitting in the residence with nothing to do. The stress of living with constant fear that his nightmare would come true and he would be returned to the institution aggravated his stomach problems.

Despite a more home-like, physically safe setting, there was the disappointment of another failure to meet Tom's modest expectations.

Moving into the community did not bring me the freedom I had dreamed about. I was still quite isolated. All the lists I made about all the things I wanted to do seem to have disappeared...

...I can have my say and express my wishes but the staff make the rules for the most part and make the decisions... As soon as I have learned to like the staff,

chances are they will quit... Some of the staff do not like helping me eat. They think it takes too long and I can feel they don't want to be bothered.

I was getting very tired and disappointed. My health was failing. I was losing weight and what was worse, I was losing hope. I did not even want to talk. I wanted to die.

Tom summed up much of his life experience in a speech against institutions. "I felt like I was in prison being punished like a criminal and all I had was a disability." Being taken from and feeling abandoned by his family both in infancy and in adolescence are wounds that could shadow a whole life. Most of the insults to Tom's humanity were day-to-day, year-in year-out experiences that grind away at human dignity and vitality: nothing meaningful to do; being ignored or offhandedly punished for voicing his perceptions and desires; surviving on a meager diet with limited medical care in a barren environment; waiting for one of the parade of arrangers and coordinators sent by the state to make good on its promises.

Tom's strategies for resistance allowed him to make do with whatever his environment made available to him. When there was more to work with –as in his time as a helper in H-Building and in the last 10 years of his life– he was better able to resist the institution trap. In my reading Tom created at least ten ways to hold on to his own life within the institution trap.

The institution isolates you and subordinates your relationships to its human management interests; **reach out and make friends**. Make friends among the people you live with and especially with those staff people who are free enough to rise above the social norms that cast staff as impersonal overseers. Keep making friends even though people keep leaving. Whenever there is a chance, make friends from outside, as Tom did when he was finally able to attend church. Tom involved his friends in his life projects; drawing them closer to him. When idled by lack of opportunities he began to dictate his autobiography to helpful staff, whom he was concerned to protect, even to the extent of keeping their names out of his autobiography's acknowledgements. Late in his life, his friends helped him make major changes in the way his assistance was organized and delivered so that he could have greater control of his daytime.

The institution discourages involvement with your family; make whatever contacts you have as nice for your family members as possible and **take nourishment from memory of those who have loved you**. Tom's remembering positive times with his mother and grandmother soothed him and inspired his dream of once again being part of a loving family. Tom is generous in his account of his father and his brothers and sisters. He welcomed their occasional visits while acknowledging that he felt that they had mostly abandoned him.

The institution controls the smallest details of your daily life, **read the environment to find cracks** in the regime. Tom found and occupied niches for himself even in difficult environments like the back wards. When he lived on a ward that didn't allow its residents outside, he noticed that smokers could leave and tried smoking.

The institution wants to silence you, **find safe ways to use your voice and don't give up just because others don't act on your messages**. When, at age 69, he encountered a resident government, he became its vice-president. When given the invitation to list his preferred activities, he did so. When he met a lawyer at work on closing the institution, he became a plaintiff. When people were organizing to close institutions, he spoke out at their meetings and in hearings. When he lost hope and the will to live, he responded to his friends' invitation and joined in planning and implementing his personalized retirement program with great pleasure.

The institution makes decisions for you to protect you from risks; **see yourself as a decision-maker and take risks to improve the chances of getting what you want**, even when the only decisions you can make concern your own attitude toward things. After being moved as a punishment, Tom decided that his survival depended on not only following the rules but helping staff out and getting them to like him. Tom moved from setting to setting to get closer to his dream. By the time of his kidney failure he had enough support and clarity of purpose to refuse the dialysis that would have put him back in a nursing home. The hospital stays during which he had to make these decisions were less stressful for him because, thanks to his friends, he was never alone.

The institution makes you dependent, **learn to do what you can for yourself**. Tom organized other residents to help him to eat so that he did not have to depend on hurried

staff. He learned to push himself in his own wheelchair. He found ways to do tasks the staff saw as helpful.

The institution has low expectations of you, **create ways to contribute**. For years Tom organized the work of other inmates to assure that people in his building with more substantial disabilities were cared for. He worked hard to finish his autobiography before he died so that others could learn from it.

The institution gets inside your head and the heads of some of the people you care about; **challenge the depression, inaction, and fear that comes from thinking like the institution**. Tom noticed the error of believing that the state's refusal to assist him to move out of the institution was because he wasn't working hard enough to better himself. Instead of trying to earn his way out by changing himself, he looked for opportunities and help to move toward his goal. When Tom's closest brother said he didn't want Tom to move from the institution, he listened but took his own course.

The institution wants to own you and your past; **tell and re-tell your own story** to yourself and anyone you can trust to listen.

The institution wants to own your future; **keep your dream alive and guard it from people who would try to kill it**. Dreams matter as guides and as a source of strength whether or not they actually come true.

I wanted to be part of the world and wanted to leave the institution. I dreamed about the things I would do when I left. I dreamed of having a wife and children, I really wanted to have a family; my own family like my wife and children. A happy family like we had been before my mother died. What I wanted most of all was to have a wife; a woman that I loved and who loved me back. This dream is what kept me going. It kept me alive. During times of despair I turned to it and it comforted me and gave me strength. I have held on to this dream all my life and never stopped hoping it would come true.

Better living conditions and more professionals do not necessarily add up to more freedom, as Tom discovered when he moved to the group home. Greater freedom to live among friends as a contributing citizen is what makes for a good life, and freedom is

what the institution trap squeezes out of people's lives. Moving on from institutions calls for learning how to dissolve the institution trap.

### **Dissolving the Institution Trap**

Tom spent his whole life seeking the assistance that he required to pursue his interests and contribute to other's well-being. In his last years, he and his friends pushed back the walls of the institution trap far enough to allow Tom personalized support during "day program hours" (six hours a day on weekdays). Lisa, an assistant Tom chose, listened to what he wanted to do and helped him do it. His desires were simple: sharing a familiar routine that begins with the daily paper; calling and visiting family and friends; going to familiar places in his community –the library, the swimming pool, the Farmers Market, shopping for foods he prefers and occasionally for clothing, sometimes visiting a bakery with particularly good chocolate éclairs; advocating for institution closure; working to find a family interested in sharing their lives and offering Tom a real home; and, sometimes, breaking routine with a camping trip, a visit to the state fair, or a trip to a family reunion or to visit a relative who lives far away. What made these thirty hours a week life transforming for Tom is that he had freedom-in-relationship with Lisa. Tom planned with Lisa to set his schedule, select his activities, and worked out what he wanted from a particular activity or encounter. Then Lisa assisted him to deal in positive ways with the way his mobility and communication impairments might interfere with his purpose (see Traustadóttir, 1991). Though time ran out before Tom was able to further escape the institution trap by sharing family life, he had the support he needed to die on his own terms, among his friends.

As great as Tom and his friends' achievements were, the institution trap ensnared him to the end. In this volume, it is for Benedikt Bjarnason, his mother Dora and his friends (Chapter 21) --members of the first inclusion generation of twenty-somethings and their families-- to discover how to align assistance so that people with substantial disabilities get to stretch the limits of interdependent community life without having first to fight their way out of the institution trap.

In 2001 Benedikt moved into his Reykjavik apartment and a bit later into part-time volunteer work with visitors to a nearby church. After Benedikt's inclusive schooling and

attendance at a residential college in Denmark with a friend and classmate who also acted as his assistant, his mother saw this as a logical next step in life as an active member of a society committed by policy to include people with substantial disabilities. Dora negotiated government support for Benedikt to be at the center of a demonstration project –Home with Support– designed to exemplify ways to realize Iceland’s goal of a regular community life for people with disabilities. This demonstration project funds the assistance Benedikt needs to live in his own apartment and pursue a personalized schedule at about the same cost as he would incur by moving into a small group home and enrolling in a day service.

Benedikt benefits from a wide network of people, many of whom he is linked to through his family and a growing number of whom have come to know him in his own right. The design of his personal assistance system –which includes a board of directors dedicated to governing his personal services, a personal agent who coordinates his activities and assistances, and paid assistants of about his own age- is adapted for Icelandic reality from approaches invented by North American families. In generating specific plans for Benedikt, Dora has consulted professional friends and colleagues as well as young people who have known him through their school years together, sometimes playing a game of “What would Benedikt say if he could talk?” Dora remains a powerful and important presence in his life even as she looks for ways to make space for his own friendships, interests, and work. Rather than Benedikt losing legal standing by being subject to guardianship, his mother holds a power of attorney that authorizes her as his substitute decision-maker,

Like any important investigation, Benedikt’s design for living trades room to learn for certainty. There are already plenty of questions to guide further learning: At what point might it be desirable to have a more stable group of assistants and how could this be achieved? Does more time at work make sense? How about work for pay? Are there ways to increase Benedikt’s ability to communicate even further? How can the personal supports from friends and other committed people be sustained and strengthened even more? How would Benedikt’s assistance be affected if his mother were less able to invest herself? What parts of Benedikt’s assistance system can be adapted by other people and

their families? What are the implications of Benedikt's discoveries for the way services are designed, funded and delivered?

So far it has been possible to pursue these important questions about interdependent living outside the net of the institution trap.

*An Agenda for Moving On from Institutionalization*

To move on beyond institutions people with disabilities and their families and allies of all ages and sorts of need for assistance need to mobilize public investment in flexible, individualized funding so that they can join Benedikt in making progress on this agenda:

- How do we move beyond treating isolated individuals toward supporting important relationships?
- How do we move beyond casting people with intellectual disabilities and their families in passive roles –patient, client, or consumer of service– toward alliances based on recognizing people's capacities to shape their own lives and co-produce necessary supports?
- How do we move beyond focusing action on professionally defined deficiencies toward building individualized capabilities through personalized and precise adaptations and assistance?

Making progress on these questions will take the courage and creativity to be inventive throughout a person's life. Regular practice of the strategies that Tom Allen used to fight off the worst effects of institutions will still be necessary. In particular it will be important for people to reach out and gather more and more people into their lives, to find positive ways to make a contribution to their community's good, to stay in charge of their own story by telling and retelling it, and to hold their dreams of freedom close.

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