# Healing Integrity Gaps

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When they need publicly commissioned assistance, people with learning disabilities[2] have to enact their freedom under more constraints than other citizens do. Many laws and policies have not caught up with the ideas that people should be able to lead an ordinary life with the support they need and that people themselves should be in charge of decision making about their lives. This means that people's lives are lived in view of many eyes and under the influence of many voices that claim the right to determine what is legal or appropriate for them: politicians, civil servants, commissioners, inspectors, investigators, managers and lawyers for commissioners and managers all have a say about the conditions under which people and those in direct relationship with them live. Almost always these voices are speaking generally about a group of people with learning disabilities. What an inspector discovers in reviewing a file and perhaps having a brief meeting is evidence to inform the inspector's judgment about the level of quality of a service, not an intervention into the particular person's life. However, when people with authority speak generally about what must and must not be done, their voices can be so loud as to drown out people's own voices and the voices of those who know and care about them.

People with learning disabilities who live a good ordinary life live in a way that is not ordinary. Most members of society experience far less scrutiny of their lives and have to negotiate many fewer externally imposed rules and limits on their autonomy than people with learning disabilities do. Without strong relationships to engage the voices authorized to oversee them, people will have fewer opportunities than other citizens do to make decisions, relate to family, friends and lovers, and engage their community.

When an organization's culture is shaped by over-attention to policy and procedure, staff and management are vulnerable to mindlessness and powerlessness. Fear of non-compliance imposes a filter on what staff and front line managers notice and the alternatives they consider. Questions are answered in terms of what those in authority assume that "they" (absent authorities farther up the perceived chain of command) want or will allow.

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[1] These are partial reflections on a workshop sponsored by Paradigm's Ordinary Life for All Network at the 7 Dials Club in London on 5 September 2014. I have described a prototype version of the process the workshop used to explore what it takes for policy and procedure to contribute to a positive organizational culture with a growing capacity to support people's freedom to pursue a good ordinary life. I will be happy if people test the process further and share their experience with me at johnwobrien@gmail.com.

[2] **Translations for readers outside the UK**: learning disabilities = intellectual and developmental disabilities; commissioners = government officials who contract for services; mental capacity = ability to decide for oneself

At bottom, support for a good ordinary life depends on relationships in which people can come to trust and believe in one another and find reasons to hope that their action can help a bit to build up a more welcoming, just and sustainable community. The fundamental importance of relationships shapes a critical lens for understanding the effects of policies and procedures. It encourages the question, "In practice, how is this affecting people's relationships with their families and allies, their friends, their support workers and their fellow citizens?" Finding answers takes more than checking that the right words are entered on the right forms. Finding answers takes time to be with people and notice and listen respectfully and thoughtfully to what they are experiencing.

Policies and procedures aim for clarity and general application. Ordinary life is particular and many situations are ambiguous, with multiple and sometimes conflicting interests at stake. If they are successful, managers who expect to control life through words on paper risk missed opportunities for realizing stated values of respect, self-direction and individualization. Ambiguity –the possibility of more than one meaningful understanding and more than one possible and meaningful action, is a necessary condition of freedom. It demands that people and those who assist them take responsibility for interpreting general requirements in specific contexts. Imposing a single interpretation of proper behavior from a distance shrinks the space in which people with learning disabilities and their assistants can exercise freedom and responsibility and learn by seeking more of what is important to the person.

The managerial burden of behavior control through written words is substantial. The authors have to identify the responses they want and then find the right words to clearly prescribe those responses. They have to find a way to clearly communicate the specific meaning that they attache to the words they have chosen to all those whose behavior they wish to influence. They have to assure compliance. Putting it this way simply exaggerates what everybody knows. People in organizations are more complex and more interesting than words alone can control.

Policies and procedures have a role to play in shaping a positive culture that supports people in the exercise of their freedom. They seem to be more useful when…
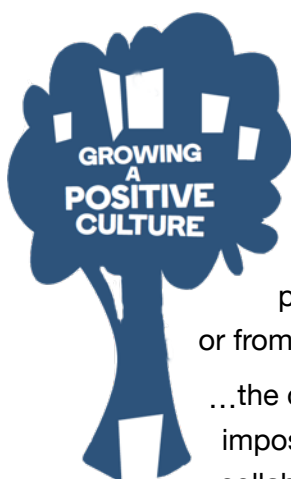


…they are deeply rooted in a continuing conversation about organizational purpose and identity in which people with learning disabilities, family members and support workers feel that their voices are heard and held with respect by others who believe in their dignity and right to full citizenship.

…the organization finds ways to stand up to pressures that undermine purpose and threaten identity whether those pressures come from within or from outside.

…the organization is clear and honest about constraints on people's freedom imposed by law or conditions of organizational operation and committed to collaborating with people and those close to them to respond to those

constraints in a creative way.

…the organization strives to develop a positive culture that includes effective structures for figuring out the right thing to do in difficult situations and a "yes, we can" attitude about constraints and obstacles.

…words that carry policy communicate good questions to ask or things to consider in particular situations rather than prescribing the details of how staff should behave or how the people the organization assists must behave.

…procedures include accessible processes that people can easily use to question behavior or interpretations of policies that result in action that violates common sense or common decency.

Useful approaches to questioning situations that don't make sense from the point of view of an ordinary life can be designed based on the idea of healing integrity gaps.[3] Integrity gaps are simply instances of failure to act consistently with purpose and identity. They are actions that staff take or decisions that staff make that don't make sense from the point of view of supporting a good ordinary life –though they might make sense from another point of view. Their source could be in policy or interpretation of policy. It might be a situation in which a an outdated story frames thinking (she can't decide, she has the mind of a 5 year old in a 30 year old body). It might be the outcome of a decision about mental capacity.

Systematically addressing integrity gaps calls on four capacities. Strengthening these capacities takes repeated cycles of trying and reflecting which help to grow a positive culture. First is desire to support the freedom to live an ordinary life. Staff and managers as well as people with learning disabilities and family members may benefit from opportunities to develop a deeper understanding of the possibilities a good ordinary life and the challenges of supporting people to live it.

Second is seeing and believing in people's capacity to live an ordinary life with the right support. Staff and mangers may have doubts about whether a good ordinary life is "realistic" for a person. Managers need to make these judgements discussable because they will be influential even if staff think their bosses will be displeased if they express doubts they do feel. It's important to recognize that some people with learning disabilities have retreated from the desire to exercise responsibility to choose and ordinary life because the assistance available to them has not encouraged them to believe that a good ordinary life is possible for them or to develop knowledge and skills. People gather a cocoon around themselves to protect from fear of what is unknown. To break through the cocoon, people need to experience being known by people who believe in them.[4] Other people with learning disabilities who are already living a good life are a very important source of inspiration and learning.

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[3] This idea is adapted from Robert Quinn (2004). *Building the bridge as you walk on it: A guide for leading change.* Chichester: John Wiley.

[4] Thanks to Jackie Downer for this insight and the image of the cocoon.

Third is mindfulness and design thinking. This is the capacity to notice situations in which there is a disconnect between stated commitment to supporting people in a good ordinary life and the way a particular situation unfolds. The size of the situation doesn't matter. Everyday examples are a good source of better understanding and new ideas. Conversation about a situation is likely to reveal the constraining influence of other voices. Design thinking is the search for a way to satisfy constraints and support a good ordinary life. People think together about how to reduce the amount of freedom people must sacrifice in order to use publicly commissioned assistance. Some limits dissolve in a better understanding; others are persistent and challenge creative effort to make more room for freedom. The process outlined below is a way to work through this stage.

Fourth is a willingness to risk trying the design for a better way, reflecting and revising.
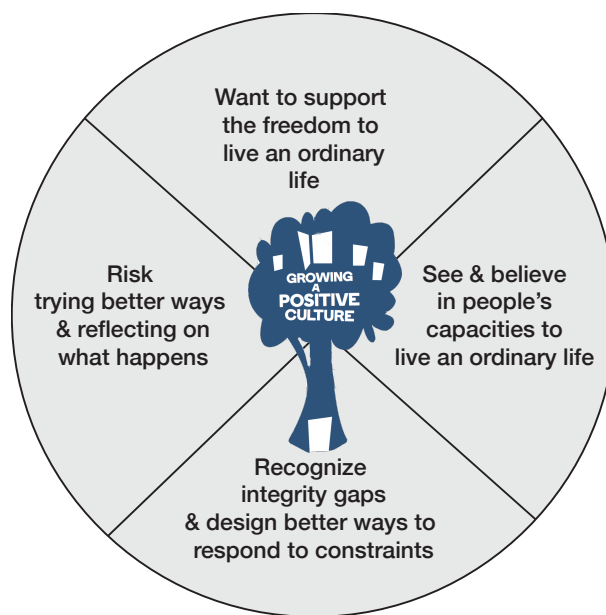


## Exploring Integrity Gaps



Positive culture grows stronger through thoughtful conversation among people with different positions and perspectives. It is through stopping to explore a situation that everyone will learn how to think through particular situations and find a way that best satisfies the multiple, and sometimes conflicting, constraints that can limit people's freedom. This process will work best if people with learning disabilities, family and friends, direct support workers as well as managers and perhaps commissioners or inspectors are active co-thinkers. If people can be curious and tolerant

enough to listen to different points of view everyone will come away with a better understanding of how to support as much freedom as possible. If people can discover a better way and have the courage to risk it, the space in which people can express their freedom will grow. Tolerance can be hard for people who believe that limiting people's freedom to choose in any way is wrong, but sometimes a way to honor people's choices comes out of an honest discussion of how to deal with the limitations that others see in a situation.

**I. Notice an integrity gap and decide to consider it**

Many limitations are imposed automatically, without stopping to think. Many people carry a version of policy and procedure in their head. This version can be a mixture of what policies and procedures say on paper and what staff have passed along to one another. or interpretations staff make up on the spot. Unless people choose to make a space for exploration, questioning staff or managers can get a defensive response that treats the question like a challenge to authority and discourages further conversation.

This step calls a time out for re-consideration. It happens when someone experiences a disconnection between a particular staff or management action or decision and the commitment to support people's freedom to lead a good, ordinary life. It may be a look back, exploring what can be learned and tried in the future from an action or decision that has already taken place. The conversation could, if time allows, explore a decision before it is final. The key is a sense that a person's freedom is threatened in a way that violates common sense or common decency.

The process will work better the more different points of view are represented. Most often this will happen within an organization with people with learning disabilities, family members, support workers and their managers. Some situations have important learning to offer senior managers, commissioners or inspectors if they can set aside their roles and join in the conversation as equals.

This step is done when people have a description of the action or decision that is the focus of their inquiry. If people describe the situation in different ways, the differences are important for learning and each version of the story deserves its own place.

**II. Identify the consequences**

Identify the positive and negative consequences of the decision or action for the person or people with learning disabilities involved, for the staff directly involved, and for the culture of the organization. People may have very different ideas about the consequences. Its much more important to practice listening to how others see the situation than it is to produce one correct list. Each person who has a comment has a chance to say how it looks for them and a chance to listen to how it looks to others. There
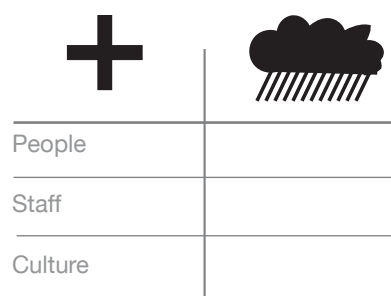
is no need to come to agreement.

### III. Sketch the causes

Brainstorm about what produced this situation and make a
map of the causes you identify. In the first ring of causes there
may be different understandings of what a policy or procedure
means: policy writers can be shocked by the understanding
that people have on the ground. There may be failure to
attend to a policy or difficulty in seeing its application. Staff
may resolve competition among stated values by fixing on
one value, like safety, and leaving others, like the dignity of risk
behind. Staff may be acting mindlessly, as if on automatic pilot. Staff may be haunted by
old stories that support taking power over people's lives and limiting their freedom. Staff
may assume that there are no possible ways around current limits in funds or staff time.
Staff may lack the competency to imaging and offer adequate support.
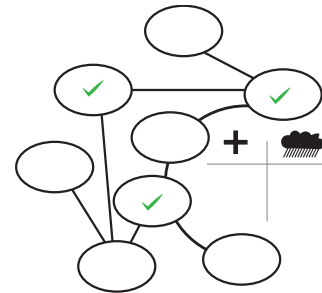
Think beyond the first ring and identify some of the causes of the causes. For key causes,
keep asking, **"How did we produce this?"**

Mark the causes that the people in the group can influence.

It can help to turn the results if this discussion into a story that explains how this situation
came to be. The story can be a straight narrative of the way different factors in the situation
work together to produce a limitation of a person's freedom that seems unreasonable or
offensive to common sense. The story can also be told in metaphor. It's important to be
alert to our common vulnerability to justify limitations by blaming the person or the person's
impairments instead of defining challenges to create better support.

### IV. Identify the positive core.

Few unfortunate situations are caused maliciously. Absent clear evidence of intent to harm,
it is worth looking again, especially at situations where negative consequences to people's
freedom dominate, to discover a positive core of good intentions. Unreasonable limits often
follow when one voice drowns out other valid voices. When people are driven by fear and
don't feel resourceful and confident about figuring out better answers, compliance with their
understanding of what is necessary for survival will dominate. Blaming people is usually a
less effective way to develop new capacity than re-framing a situation as one in which
pursuing one positive intention got in the way of considering other good things. This invites
people to move from a narrower to a wider view and raises the possibility that it might be
possible to serve more than one valid interest at a time.

All, or most all, policies and procedures have a positive core intention to benefit people with
learning disabilities directly or indirectly. Some policies may reflect a poor connection to the
deeper purpose of supporting people's freedom to live a good ordinary life and therefore
need revision. Confusion about mental capacity entangles some policies and procedures

and their interpretations. Lack of competence or imagination about how to support people with complex needs for assistance may lead to mindlessly overlooking their right to a good ordinary life. But with all these imperfections, it is rare that a policy or a staff gesture lacks a positive core even when its effects impose limits.

This can be so even if it seems that the only value that staff and mangers are serving is organizational survival. Here the positive core could be continuing to support a person and the next step is to figure out ways that preserve the relationship with the person AND offer the person greater freedom to live a good ordinary life in which they have control. Note that attributing a positive core is an interpretation of possible intentions and might come as a (pleasant) surprise to the actors in the situation if the attribution is offered as an honest expression of possibility.

To discover the positive core, keep asking **"What positive value could this serve for the person with a learning disability?"**

**V. Design a better way**

Design thinking looks for better ways to satisfy the constraints in a situation. Review the discussion, especial the cause map, and identify the most significant limits on people's freedom in this particular situation. Then ask the design question: **"With the resources and authority we have right now, how might we satisfy these constraints AND promote or protect people's freedom to live a good, ordinary life?"**

> Instead of an inflexible, hierarchical process that is designed once & executed many times, we must imagine how we might create highly flexible, constantly evolving systems in which each exchange between participants is an opportunity for empathy, insight, innovation, & implementation. Every interaction is a small opportunity to make that exchange more valuable to & meaningful for all participants.
>
> –Tim Brown
> *Change by Design*

To ask the design question doesn't guarantee a positive answer. Not to ask the design question certainly leaves people stuck. Trying a better way is likely to involve some risk. The best way forward might call for negotiation with senior managers, Commissioners or Inspectors, a process that will take time if it is possible at all. It may be that the best way forward that is within the control of those involved still seriously compromises people's freedom. The expectation is not perfection but a meaningful increase in people's freedom and a greater sense that people and those who assist them are not alone and powerless to try a better way.

This process only addresses one of the conditions for healing integrity gaps. It helps people who have noticed a threat to people's freedom to get more clear about the gap and its consequences and search for better ways to understand and respond to demands that affect the expression of people's freedom. This will do no good without leadership that cares deeply about expanding people's freedom to live a good ordinary life and without ability and willingness to see and mobilize capacities. It will lead nowhere if people are unable to take enough responsibility to risk trying a better way and learning from it.