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Transformative inclusion management

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Transformative Inclusion Management

> The problems of life are insoluble on the surface…
> Getting hold of the difficulty deep down is what is hard.
> Because if it is grasped near the surface it simply remains the difficulty it was.
> It has to be pulled out by the roots; and that involves our beginning to
> think about things in a new way. …
> The new way of thinking is what is so hard to establish.
>
> (Wittgenstein 1980)

This anthology provides resources for developing the new ways of thinking that provide a good hold on the transformations necessary to support inclusion. Considering how transformation might be managed rescues inclusion from treatment as a concept to analyze or a daydream to fantasize by focusing on managing the co-creation of transformed social relationships. It offers ideas that address the conditions that make inclusion and transformation challenging. There are links to practices that bring life to transforming the relationship between people with disabilities and their communities.

One of this book's strengths is that almost every reader will find some chapters difficult to read because they find themselves in conversation with a new perspective on inclusion. This in itself is a lesson: inclusion and transformation are emergent phenomena. As long as we continue to seek broader opportunities, deeper understanding, and more diverse alliances, new meaning will continue to open to us. Managing transformation animates the joyful and relentless pursuit of more and more life-giving answers to the question, "What more is possible?" For this person? For this neighborhood, workplace, community? For this team, organization, school, system? (O'Brien & Mount 2015).

Beginning to think about inclusion in new ways is hard because the necessary vocabulary and grammar remain unfinished. New thinking develops through reflection on action in uncertain social territory: next steps into meaningful participation in the same schools, housing, workplaces, civic and leisure activities experienced by people who do not require accommodation and assistance. Far from a precisely delineated and metered goal to be attained, inclusion is an ever-expanding network of intersecting social pathways to be discovered. Far from marching people through well mapped steps to predetermined best practices,

managing transformation is orchestrating an adventure to explore the possibilities that show up when groups of people with diverse perspectives reconfigure their boundaries, achieve a shared awareness of their situation, and act to question accepted limitations on flourishing life (Meissner 2013; Scharmer 2022a; 2022b).

The assertion that inclusion is an open and unfinished ideal by no means reflects a consensus. Plenty of good people are sure that their understanding is complete as it is. Some go as far as to say that their current reality exhausts all possibilities for inclusion. Plenty of committed advocates and administrators believe that writing rules that demand inclusion and offering technical assistance is sufficient to achieve transformation. It is difficult to learn when you are convinced that you already know, so managing transformation involves supporting people to let go of their certainties and get excited about becoming social innovators.

Beginning to think about inclusion in new ways is hard because supporting socially excluded people to take up valued roles in ordinary community life is hard. Social exclusion is a palpable force delivered through segregating, controlling structures erected on partially obscured stories of irremediable incapacity, vulnerability, inferiority, pity, and menace. When these stories prevail, the need for protection, supervision, and treatment is self-evident. The special school, the day center, the group home, the nursing facility become the necessary sources of the expert attention people need. Indeed, as a consequence of social devaluation, many people and families have experienced hurtful rejections, bullying, exploitation, and hate crimes. They may adapt to social exclusion by making a life that offers activities, positive rules, friendships, and intimacy within the borders of family and service settings (O'Brien 2010). What looks like marginalization from a strong view of inclusion can look like sanctuary from within the walls of special buildings, among people with no lived experience of inclusion. Managing transformation can't proceed by assessing readiness for community life and pushing people out into it. It proceeds by noticing and supporting the desires and interests of those who want to risk finding new paths into community life. Establishing the practice of deep listening as the necessary foundation for co-creating valued community roles is the core of managing transformation. The appreciation of a person's gifts and capabilities that often emerges from careful listening energizes a journey of discovery.

The designers of most current services assumed, often implicitly, that people with disabilities belong with "their own kind" under (benevolent) supervision by medical or paramedical staff or special educators who train, teach, and perform tasks that shape a person's routines. Inclusion will attract transformational change only among people who share a conviction that it is both possible and morally right to seek more and better experiences outside the world of special places for special people. A key move in transformation shift the conviction that all that's necessary for a good life is stocked within the walls of special schools and services to a

realization that there are good things to seek beyond those familiar boundaries. This shift is best achieved in action, co-creating a role "out there" with a person who has been a special class or service insider. Managing transformation involves establishing a contrast to the devaluing effects of old ways of thinking. Reaching out to learn from places of potential inspires and informs this work.

Many places of great potential move outside the disability orbit, among other groups organizing to overcome social exclusion and inequality. Making real connections at the intersections of disability with race, class, and gender identity will bring new possibilities for alliance, additional strategies, and insights like this description of the inner work of resistance, from a leader in the movement against racism and economic inequality.

> "If structural violence is a series of societal agreements to not pay attention to a set of people we deem less human than ourselves, as I believe it is, then what does it mean to cultivate a quality of attention that redresses these agreements? Not averting our eyes from the systemic racism that shapes our collective existence is core, as is witnessing with a tender heart. Then connecting the tender heart to effective action means acting with understanding of the urgent need to see from the whole, which cannot exclude anyone, especially people who have been marginalized." (Cunningham 202, 10)

Beginning to think about inclusion in new ways is hard because the work has both outer and inner dimensions. Transforming resources assembled to supervise and treat groups into individualized supports for contributing citizenship is not only technically complicated, it is hard emotional work. Many have a stake in services that accept full delegation of responsibility for the health, safety, development, and happiness by turning people into full time clients. People with disabilities may adapt their preferences, believing that familiar roles and relationships at the margins define the inevitable horizon of their lives. Many families seek relief from being the main source of assistance even at the cost of social exclusion. Many families yearn for the long-term security of a tangible service administered by experts and held accountable to the state for quality of life. Good people, including leaders with disabilities, have invested their careers in developing good places for vulnerable people to live and spend their days and are loyal to their creations and those who helped make them. Workers have organized their lives and livelihoods around meeting predictable responsibilities. Organizations have worked hard to acquire and improve buildings and materials. State actors, political and administrative, have struggled to win the resources to deinstitutionalize and establish group-based services. Meaningful efforts at transformation work through conflicting loyalties and support expressions of loss and grief.

One price of transformation is repeated discovery of blind spots that have entangled change makers themselves in practices, structures, and stories that reproduce social exclusion and diminish the agency of those they would include as equals.

Building relationships that can hold honest acknowledgment of these entanglements and acts of reparation and forgiveness is an important function of managing transformation.

Beginning to think about inclusion in new ways is hard because, at least in the time and place I am writing from, change makers are tired. Years of austerity and underinvestment made sustaining a capable and committed workforce problematic even before years of pandemic. The rate at which the field is learning from the achievements of pathfinding people with intellectual disabilities and autism and their allies feels infuriatingly slow. Demonstrating compliance with a growing accumulation of bureaucratic rules colonizes more and more attention. Managing transformation proceeds by claiming time and space to build shared awareness by listening, journeying to places of potential, and renewing a sense of highest purpose. This space creates a platform for co-creation that grounds change makers in a source of renewal: discerning and stepping into an inclusive future.

Beginning to think about inclusion in new ways is hard because the individualized supports necessary to transform the experience of socially excluded people rest uncomfortably with the way states fund and administer long term supports. Using a personal budget to organize carefully matched support workers to form a self-managed team that accompanies people as they take their place in community looks flimsy to an administration designed to manage a network of providers expected to deliver care and treatment to groups. Neo-liberal management practices undermine the relationships and flexibility necessary to the work of inclusion. Cost control through stringent time and task specifications treat support workers as interchangeable parts and meters assistance as standard transactions. Risk management driven by fear and distrust works to keep people enclosed. Austerity measures are justified with the claim that more can always be done with less.

Approaches to planning described in this book also are a shaky fit with the ways of knowing that are credible with most authorities. Numbers based on scientifically validated assessments of deficiency seem more real that visions crystallized from deep listening and imagination. Statistical models, survey data, and attempts to imitate drug trials, seem more reliable than observations on changing horizons or stories from lived experience. Professional diagnosis and prescription seem more efficient and defensible guides to decision making than a process of co-creation that follows a direction of travel set by people with disabilities and their allies. Managing transformation authorizes dialogue among different ways of knowing and deciding.

Beginning to think about inclusion in new ways is hard because the greatest opportunities lie in complex challenges that require inquiry and multiple social innovations. Taking journeys into territories yet only partially mapped questions what is taken for granted in settled stories. Co-creating better supports for people with disabilities to exercise decision making power shakes the foundations of most

existing forms of service. These four points for managed transformation are rising on the horizon.

- *Develop supported decision making and alternatives to guardianship* (IRIS 2021). Article 12 of CRPD (The UN Convention on the Rights of Persons with Disabilities) turns over the reflexive placement of people with intellectual disabilities under some form of substitute decision making. Working out practical ways to recognize that people with disabilities have legal capacity equal to others in all areas of life and providing the support they require in exercising their legal capacity will stretch thinking and practice into new territory.

- *Sharpen awareness of restrictions on people's freedom and co-create ways to reduce them*. It's easy to assume that a person who is not in an institution is living in the least restrictive possible situation. In the *Cheshire West* case, the UK Supreme Court ruled that a person is deprived of liberty in any service where they are "subject to continuous supervision and control" and "not free to leave". The Court applied this standard not only to congregate facilities but to supported living, and shared living with a family. As Lady Hale put it, "The fact that my living arrangements are comfortable, and indeed make my life as enjoyable as it could possibly be, should make no difference. A gilded cage is still a cage." This result does not forbid such arrangements; it establishes that an English or Welsh person living under these conditions is due legally available safeguards. The wider messages are that any service setting should be regularly swept for unquestioned restrictions on freedom and that co-creating supports that increase freedom is a worthy purpose for transformation (Series 2022; O'Brien & Duffy 2022).

- *Co-create ways to expand use of person-directed individual funding and focus it on supports to valued roles in community life*. A variety of established forms of personal budgets demonstrate the potential to increase the effective control people with disabilities have over their supports and create the flexibility necessary to individualize support for inclusion (Duffy 2021). When this capacity is surrounded by a variety of resources– including advice and instruction from others who share the experience; practical help with the tasks involved in organizing and directing a personal support system; and community building initiatives – conditions are right for doing the work of inclusion.

- *Adopt citizenship as the frame for understanding the relationship between people with disabilities, their communities, and the state* (Citizen Network 2022). This perspective surrounds attention to the social exclusion of people with disabilities to embrace everyone in the right and responsibility to create a world where everyone matters and each plays a valued part. This is an important corrective. It counters the devaluation of difference and relegation to the role of passive recipient of social care with a call for active, contributing citizenship. This brings action in pursuit of the common good into the new thinking.

Those who dare to think of transformation as something they are called to manage accept responsibility for bringing diverse people and organizations together to co-create new social forms, forms whose emergent character cannot be fully specified and controlled. When the aim is transformation of social exclusion, it takes courage and creative energy to act. This book encourages and informs those who dare to commit to inclusion.

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