Some lessons concerning agency transformation towards personalised services

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Abstract

The International Initiative for Mental Health Leadership (IIMHL) is a joint endeavour involving eight countries, and aims to facilitate the sharing of best practices and to provide support and collaboration for leaders of mental health services to develop robust and effective managerial and operational practices. The ultimate aim is to improve services for people who use them. An article from the IIMHL is included in every issue of *The International Journal of Leadership in Public Services.*

This paper describes the key learning outcomes that came from the examination of the experience of eight American community-based agencies that altered their service practices from an exclusive reliance on group and fixed models of service, to models of service that were exclusively individualised for the entirety of the people they served. It examines the key lessons learned as to what drove this process and what did not, as well as what some of the critical comparative outcomes were. A significant core factor cited repeatedly was values-based leadership from within the agency concerned and a key result was that individualised services for every person served were very cost competitive in the systems they were in.

Key words

international; agency transformation; service models; support; personal and organisational leadership

The challenge of the individualisation of services

Many service models are quite set or fixed in nature so that a kind of standardisation of practice becomes entrenched. If the service model and subsequent practices become rigid and entrenched, then there is a very real likelihood that the service will persist with upholding its service model ie. its fixed pattern of practice, irrespective of whether it meets the specific needs of the people that might rely on that service or not.

This might not matter if the needs of the persons served were themselves quite alike and standardised, because a set or fixed response that was relevant to such needs would make sense, since there would be symmetry between what is needed and what is provided. For instance, if the service was set up to deliver a relatively straightforward intervention, such as explaining a new systems eligibility criteria to prospective service users, then a standardised approach would likely work reasonably well.

Hence, there may be at least some merit in a closed and limited 'menu' driven service model.

However, as human needs become more complicated and diverse in nature, it becomes increasingly more appropriate to alter service responses to more precisely fit the specific needs that are present or emerging. This avoids the dangers of providing supports to people that are irrelevant to their specific and unique needs, of offering the wrong degree of potency of support and even possibly damaging people because what is offered is somehow toxic in terms of its effect on them as it is contrary to what they need. Nonetheless, a good number of our services today are not responsive in this sense and this will result in the person being fitted to the 'set' or 'fixed' service model rather than the service model and practice altering in accordance with what is actually needed by the person. The service model perpetuates itself, rather than changes, to meet the varying and specific needs of those seeking service.

The response to this challenge has often been seen as a need to create the types of service models that essentially guarantee a targeted individualised response to the specific and unique needs of each of the persons being served. Further, a service model is needed that results in distinctly individualised options on a person-by-person basis and that these are driven by what the person needs. In its most systematic expression, it may mean some measure of capacity to design individual solutions to the person's needs that are built from scratch or built from and around the person's needs.

The necessity of agency transformation

To achieve such widespread individualised outcomes would require the presence of agencies that could transform themselves from standardised group and fixed models of services to individualised ones, or the deliberate formation of new agencies whose service models are essentially individualised from day one. Given that the vast bulk of current human service resources are already invested in the former, it is easy to see that if the goal of there eventually being significantly more individualised tailor-made options available on a widespread basis is to be achieved, at some point we would have to be able to convert the present stock of fixed model services to ones that routinely create individualised options.

Otherwise, one could only individualise with new monies, since all of the old and recurrent monies are tied up in fixed models.

Should these funds not be able to be unbundled from conventional service models and be in turn spent in individualised options, then no system would be able to deliver individualisation except to the few who were able to access new monies. There are obviously a good number of community agencies in existence that are now using recurrent funds in creating exclusively individualised options, but they may have skipped the phase of converting from group to individual options since they had essentially started with individual options rather than converted to them.

The need to examine the evidence offered by existing examples of agency transformation

It is precisely this question of whether agency transformation of this kind can take place under real world conditions that is at the heart of the question of whether individualisation could survive as a credible goal of service systems. On another level, if community level agencies cannot actually first convert from fixed models of service to individual options, then personalised service options will progress no further than being goals that cannot get implemented. Further, if these same agencies cannot individualise for all of the persons served without exception, then there is a risk that individualisation is only viable for some, but not all persons served.

Further, if the agencies then found that they could not sustain individualisation indefinitely into the future, then this might suggest that systematic and widespread individualisation is impractical. Finally, if it was only agencies in specific jurisdictions that were able to succeed, or in specific financial, bureaucratic or political regimes, then there would be the question of whether or not individualisation was feasible across multiple environments, some of which may be more or less favourable to upholding individualisation.

The only way to know for sure whether these feasibility questions could be answered affirmatively in favour of individualisation would be to locate agencies from multiple locations and jurisdictions that had successfully transformed themselves from group to individualised options for each and everyone they had historically served in group models or that they had drawn from group models. Further, such agencies could also demonstrate that they could sustain individual options for a sizable time without any interruption of individualisation.

If such outcomes could be achieved by even a handful of agencies, it would suggest, at least,

prima facie evidence that at technical performance and possibly other levels, systematic agency transformation towards individualisation could be potentially feasible if other agencies faithfully followed the same approaches taken by these pioneering agencies.

A special conference to examine the experience of demonstrated long-term agency transformation

With this question of feasibility in mind, the North Carolina Developmental Disabilities Planning Council hosted a four-day national conference in May of 2007 in Asheville, North Carolina to showcase a sample of agencies from within the United States that together met the criteria already mentioned. Led by a small group of conference planners, it was decided that eight agencies would be selected that had already engaged successfully in agency transformation and had demonstrated that it was able to create an individualised option for each of all the people it served without exception and that it had been able to sustain and evolve these for a minimum of at least a decade. Lastly, it wanted agencies from a wide variety of states in the country.

Eight agencies, from both urban and small town locations in seven different American states, were selected as being examples of successful pioneers in agency transformation towards individualisation. These states were California, Louisiana, Massachusetts, New Hampshire, New York, Washington and Wisconsin. Some of the agencies had, in fact, been totally individualised for 20 to 30 years already and some were more recent, but all of them had been totally individualised for at least a decade. Individualisation was judged to be that each person served had a distinct individual support arrangement. The agencies were all from the disability sector and principally, though not exclusively, served adults. They also had a mix of residential and day/work services, as well as other foci such as family support.

Each agency was asked to provide a detailed profile of the basic facts about itself so that its lengthy plenary presentation could focus on its description of how it had precisely transformed itself in the direction of individualisation. This was followed by an opportunity for those persons in attendance at the conference to question the example agencies on any matter that was of interest to them, both in plenary and informally during the conference. Each agency essentially had almost a half day to tell its story.

In light of the fact that even with these generous amounts of time, not all questions or aspects of agency history could be pursued to the extent that would satisfy the inquiries of some conference participants; it was offered that such participants could continue with their inquiries directly with the agency after the conference was over. It should be noted that the conference organisers did not independently evaluate the many facts and claims of the agencies, so it is conceivable that some of their portrayals of themselves might not be entirely accurate in every respect. To have done so would have been hugely expensive and time consuming and would have been a divergence from the main aim of the event, which was to explore, in an initial sense, what might be involved in actually achieving widespread individualisation.

Some of the key lessons highlighted by the example agencies

What follows here are some of the more notable lessons that these example agencies repeatedly demonstrated. They are presented here only very briefly, so as to give an overview of what their experience had demonstrated. Obviously, such a thumbnail sketch is inadequate in properly conveying much important detail or in explaining what might account for the patterns observed. Nonetheless, it does point to factors, assumptions and theories that may challenge much of what may be presumed about the individualising of services by persons who have not yet actually accomplished it.

The agencies had individual options in place for the entirety of the people that they served

The agencies had found that they could transform group and fixed models of service to individualised options and that they could do this with all of the people that they had been serving and sustain these indefinitely. They were all careful to point out that this had not always been easy, nor that their efforts at individualisation were always of good quality. They all described the task as challenging and full of struggles and setbacks. Nonetheless, despite these and other caveats, they all reported that they were convinced that wholesale individualisation of this kind had proven to be feasible for them. No any agency declared a sub-set of individuals as not being feasible for individualisation.

No agency had reverted back to providing group or fixed models, though there were a few instances of some individuals who had elected to opt out of their services and who re-entered conventional services.

In every instance, the agency had offered to continue to serve the person in an individualised arrangement. As such, they had not broken with their commitment to individualisation, but did respect the choice of the person to go elsewhere. It is notable that the people served represented a largely stable group that had been served continuously over time by the same agency.

Agency level individualisation happened in service systems that were largely not pursuing extensive individualisation

It may be assumed by many that individualisation at the agency level can only occur if the whole surrounding system is pursuing this goal simultaneously, on the premise that an *a priori* systems commitment to individualisation is a necessary precondition of agencies being able to individualise their services. In fact, the agencies that presented were often either the only agency they knew in their state who had entirely and systematically converted from group to individual service models or that the number of other agencies that had also done so was very small. It is notable that these agencies coexisted right alongside other agencies that had no specific interest or commitment to individualisation.

More often than not, these agencies were the initial early adopters of individualisation and were in the extreme minority in comparison to agencies that largely relied on group or fixed models of service. Nonetheless, these agencies were thriving and succeeding, in terms of what they offered service users by way of tailor made options despite their embrace of a very divergent path relative to the majority of agencies.

The impetus to individualise principally came from values-based leadership within the agency

The assumption that some people might make would be that individualisation would arise only as a response to systems mandates and that agencies that proceeded without it would be stymied by such a system. This was not the case whatsoever with these example agencies. The decision to individualise came entirely from within each agency, though some of the agencies acknowledged that they had been deeply influenced and inspired to do so by people and examples external to them. What seemed to have been decisive in each agency's story were the values and leadership of key people in the organisation, both solely and collectively

who championed the goal of agency transformation towards individualisation and helped overcome whatever stood in the way of this occurring.

In most instances, the decision to entirely individualise their supports was controversial and even divisive internally. Further, their individualisation approach often was not a normal provision of the system, so the agencies often faced the need to collaborate with their funders and others to find a way past whatever bureaucratic hurdles were in their way. Frequently, they were assisted in this task by people in bureaucratic and systems roles who supported their aims. Nonetheless, the principal driver was internal agency leadership that emphasised the values of personalised supports, with the agency directors being a key component of this.

All agencies believed that they had achieved what they had with individualisation by simply moving ahead with individualisation one person at a time, no matter what

The agencies did not emphasise the outcome of systematic individualisation so much as their method of advancing by engaging and resolving issues with a given person one person at a time. As each person's situation became more individualised, this helped lead to the more macro net result of increased overall individualisation of lifestyle and supports. In another key sense, the agencies were asserting that each individual being supported constituted a key test of responsiveness by the agency to that person's needs at a given moment. Should the agency fail to be of help, then it would mean that the person would do less well. So, for these agencies, the concern was not whether a response was individualised, but rather whether this response was relevant, effective and beneficial.

No agency believed that they had been given, or had they expected any guarantees in advance from the system that their individualisation would be supported

Though many agencies might prefer to be reassured in advance that they would face any risk or tribulation by entering a change process, such blanket assurances are not likely to be offered by any system. It is noteworthy that these agencies did not expect nor did they pursue such assurances. In each instance, they went ahead simply on the conviction that this is what the people they supported most needed and wanted and they would pursue these aims on that basis.

In this regard, these agencies recognised that they would have to act as trailblazers and pioneers and that would mean undertaking a sizable measure of sacrifice and challenge on their part. In this, they also recognised that they might well be the odd man out in their system and were willing to accept whatever price they might have to pay for this. At the same time, they did repeatedly acknowledge, with considerable gratitude, the support and encouragement they had received from many people both in and outside the system on both official and informal levels over the years.

The net costs of individualisation in the aggregate were within the range of normative per capita costs in that system

A common objection to the proposition of widespread individualisation is that it would not be affordable, ie. the presumption being that group services are inherently and inevitably cheaper. Undoubtedly, much of this thinking is premised on the idea that all individualised services would have as a basis, one-on-one staff on a 24/7 rotation cycle. While most of the agencies did have some such arrangements, it was notable that these options were only some of the mix of supports that they had developed. Consequently, when their overall costs were averaged across all of the people they served, the cost per person was comparable to or less than the average per person cost of service, (in the system they were in), for people with relatively similar needs.

All of the agencies had been able to maintain a balanced budget throughout the entirety of their period of individualisation

Though the agencies had better and worse financial years and were subjected to the same cyclical financial circumstances faced by all of their peer agencies, they had never failed to maintain a balanced budget on a year-by-year basis. Though many agencies that have not tried systematic individualisation might fear that it would somehow break the bank, this did not seem to be the case at all. The agencies did acknowledge that they had had to be extremely frugal and intensely fixated on their goal. Further, they acknowledged that they often had to make many sacrifices in order to achieve their goals. However, they saw this price as an inevitable cost of creating change for the better and were willing in most instances to do whatever it takes.

All of the example agencies were fully compliant with system and funder requirements

It is conceivable that some people might presume that going down the route of individualisation would be so anomalous that the agency might imperil its ability to be supported by the broader system due to a failure to comply with its requirements. This was not the case – not one of the example agencies had had this experience. Rather, they all reported being in good standing with all of their funder and system requirements and most reported being in the exemplary compliance category in regards to these. This is not meant to suggest that these relationships were always easy and harmonious, but rather that they were well within the normative range. Put another way, while some people might have seen their service model preference for individualisation to be radical and even somehow risking the disapproval of the authorities, this did not turn out to be true in practice. More common was that the funder often, but not always, saw such agencies as being welcome leaders and innovators.

The agencies were comparatively small

These example agencies were notable in that they were relatively small in size and in some instances, quite self-consciously preferred to be small due to their belief that the quality and viability of their efforts at individualisation were better if the size of the agency did not get too big. The largest agency of the eight had a budget of $14 million. Most were considerably smaller. Presumably, transforming a smaller agency might be easier to achieve than might be the case with a bigger, more complex and possibly more entrenched agency. Further, it is notable that no agency larger than $14 million in budget size was identified anywhere in the United States that had successfully achieved the same systematic individualisation as these smaller agencies had. Such agencies might conceivably exist, but their identity had not been pointed out by any of the available informants that were asked.

Consequently, the conference organisers were unable to find a single example of a larger agency, at the time of the conference, that had either specifically committed to such systematic individualisation, quite apart from achieving it so that all persons served were now exclusively in individualised options. Only one of the eight agencies was somewhat large in size in either financial or the number of people served senses. Many large agencies that had some examples of individualisation were noted, but typically these

agencies had not chosen, as yet, to systematically individualise services. Not unexpectedly, what was discovered to be in considerable abundance was person-centred rhetoric and goals, but this did not seem to be associated with the actual formation of systematic individualised options. This made it all the more interesting as to why at least some agencies had been able to do better at turning goals into actual person-by-person support arrangements.

Respect for and effective engagement of families and other natural supporters

Most of these agencies emphasised the valuable contributions that families and others had made to the lives of the persons being supported. Rather than portraying families as burdened and in need of respite, they typically saw families and others who played family-like roles as being a potentially invaluable resource that made supporting the person much easier on many levels. On another level, these agencies saw that the contributions that families and other natural supporters made were particularly important. These included freely given relationships, commitment, independent advocacy and safeguarding and access to broader community networks and membership groups. In addition, many families gave exceedingly of their time and monies towards supporting the lifestyle of their family member with a disability. Not all families are equally positioned in either time or money, but they often give of what they do have in good measure. Inherent in these recognitions of family contribution is the value of agencies entering into and upholding good partnering relationships, so that the service user would have both what the agency could offer and what flowed from family and community ties.

The agencies served their share of very-difficult-to-serve persons

The agencies were able to serve people that were considered by most people to be very challenging to serve on an ongoing basis and none reported abandoning such persons in order to make it easier to individualise. In fact, the agencies were pleased that they had been able to support such persons, as they believed that it was both a testimony to the values that they embraced and the fact that most of these people were eventually doing much better in individualised arrangements than they had been doing in more conventional ones. They emphasised that achieving these sorts of results had been taxing in all sorts of ways and that it would be wrong to

conclude that, even at present, they were still facing many struggles to get things right for particular individuals. As such, their claim was that they were managing nonetheless to support such persons within individualised support arrangements on a sustained basis.

All of the agencies had in place some form of functional individual budgets

The premise, at least in some circles, is that the individualisation of supports is impossible except in systems that overtly provide individualised funding to individuals. Others might assume that agencies would not co-operate with individualised support arrangements except in instances where this is forced on them due to the service user being in control of the purse strings. It is notable that, in the case of these eight agencies, the agencies not only supported individualisation, they saw themselves as champions of it. They also had no apparent difficulty maintaining a set of internal individual budgets that divided up systems resources such that each person's costs of service were linked to their unique personal needs and priorities. In most cases, these were informal budgets, but workable nonetheless for purposes of planning, implementation and partnering with the agency.

All agencies were able to coexist and thrive throughout multiple changes in political parties, administrations and policies

The longevity of the period of systematic individualisation across these agencies varied from 10 years to over 30 years. In the intervening time in these seven states, there had been regular changes of state and federal political parties, as well as an ongoing change of bureaucratic leadership at both the state and federal level. The systems around these agencies were in constant change and these changes did not seem to have been ultimately fatal to the agency's pursuit and sustenance of individualisation. This is not meant to suggest that some of these changes had no effect whatsoever on their practice of individualisation, but rather that the agencies eventually found ways around whatever adversity they might have created. In reality, some of these changes were serious enough in their consequences to potentially imperil individualisation. Even so, it is notable that none of the agencies had thus far been ultimately stymied in their efforts to individualise.

All agencies saw their principal task as developmental and ongoing in regards to a person's life at a given moment

What was happening (or not) in people's lives and their resultant needs were what dictated priorities for the agencies. Their emphasis was not on simply starting a given individual support arrangement, but rather the challenge of being able to address whatever might come up in people's lives. All of the agencies emphasised that upholding a person in their lives was a constant challenge as life was continually changing for the people supported, and the agency had to usefully respond to these changes if it were to remain faithful to the person and their well-being. Thus, the agencies did not believe that by individualising services they had somehow arrived at a point of success and could, therefore, relax. On the contrary, the individualisation of supports was merely the beginning of their continued involvement with the person and the issues that arose in their lives.

All agencies believed that vision and values for people's lives were much more important than money as a determinant of good person-centred outcomes

Though it is not hard to find people who claim that they would do better with people's lives if they had more monies available to assist them, this was not the consensus among these agencies. Rather, their belief was that the key factor in shaping good outcomes for people began with and was guided by the clarity and positive nature of their vision and values and whether these were meaningfully applied in people's lives. They were appreciative of being able to access financial resources and would not claim that monies were irrelevant. Rather, they instead emphasised the qualities of the people they enlisted in paid and unpaid roles and the impact of these qualities on the sense of hope and promise in each of the lives of the people supported. In this regard, the agencies believed that they had better than average staff retention and took great care to select, keep and nourish the people that brought the qualities they most admired and enlisted in their support of people and their lives.

Conclusion

This conference was instructive, both for its clarification of what the active ingredients are in achieving widespread, if not systematic, individualisation of supports, and lifestyles from a base where the majority of people supported

are in fixed group service models. In this regard, the conference's emphasis on personal and organisational leadership and the role of vision and values is notable as key precursors to embarking on the person-by-person pursuit of individualisation. This is in striking contrast to the belief that only systems can create individualisation and that people and agencies must wait until such systems make up their mind. Further, despite the widespread presumption that individualisation would be unaffordable in most systems, these agencies have demonstrated that it is actually quite feasible financially providing that the given agency is frugal, determined and emphasises the role of quality in those who provide the support. This will be good news for those people who still seek the possibility of each person having a unique lifestyle and supports.

Note

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Addenda A

The eight agencies who presented at the service transformation conference in Asheville, NC, US, May 2007.

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