

Themes from the Quality Assurance Committee Participatory Action Research

October 2015

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Vision Management, Participatory Action Research Ideas for Action 2015

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Enhancing Meaningful Person-Focused Supports

I. Introduction

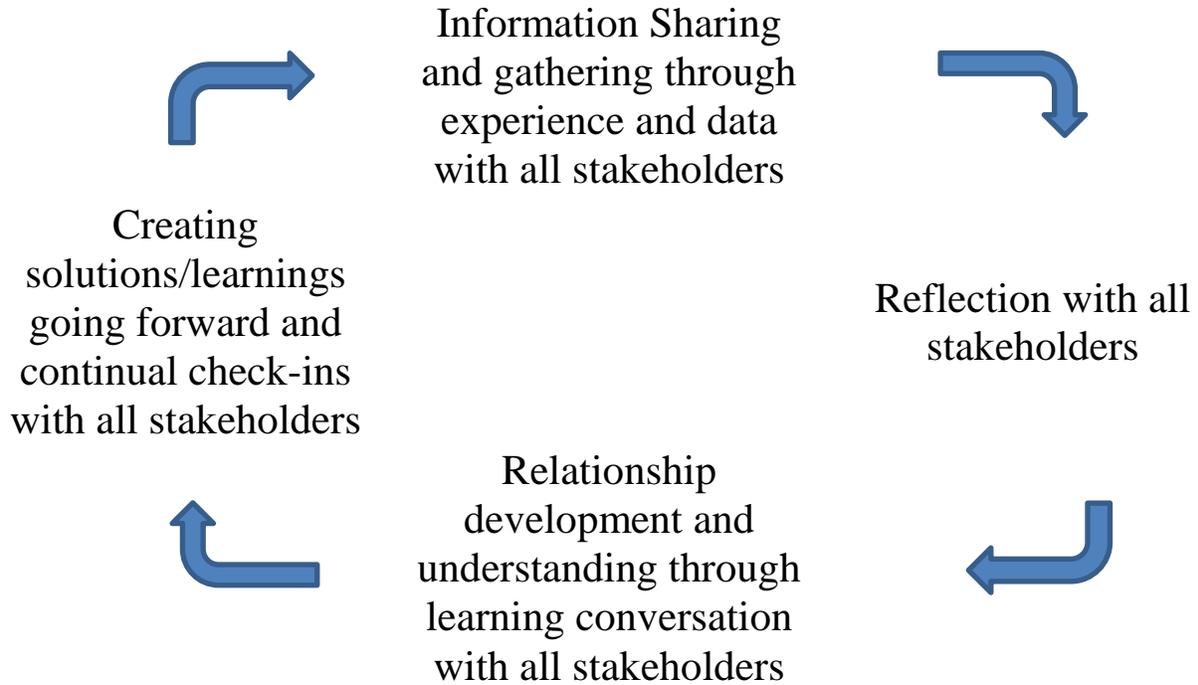
In 2000, PHSS initiated Participatory Action Research as a bi-annual review process. It began as an instrument to measure satisfaction, compliance and accountability and in the last 15 years it has evolved into a tool which motivates and grows a culture of improvement and reflection, allowing for meaningful and responsive change. It builds on the experience of stakeholders to create a resilient support system based on what is important and meaningful as defined by the individual and their family.

The incorporation of the concepts and learning from the PAR process have led us to integrate the ongoing interactions, quest for knowledge and reflection, resulting in the creation of options and/or solutions. From being an evaluation of a “snap shot” in time, this process has evolved into an ongoing integrated observation. It encourages reflection on the day to day relationships, response and experience of those we serve, those who provide the service, their families and our community. It has changed from a picture of services into a way of supporting people to enjoy a meaningful life, as defined by them.

We have moved to encouraging and supporting a culture of shared understanding in order to create solutions by...

- Beginning with evidence and experience of stakeholders
- Valuing the feedback of all stakeholders
- Listening without defensive posturing
- Encouraging constructive, critical reflections
- Creating a response/action that considers all stake holders
- Committing to move forward to ensure continuous improvement

PAR Process
Create, Solve, Review and Reflect



II. Brief History of Participation House Support Services and the PAR Experience

History of Participation House Support Services and the PAR Experience

Established in 1988, Participation House Support Services - London and Area is a non-profit, community-based organization providing assistance to people with significant physical and/or developmental disabilities to reach their full potential at home and in the community. It is committed to encouraging and creating an inclusive community where individuals with disabilities have access to all the community has to offer and are included in a valued and meaningful way.

PHSS is funded by the Ministry of Community & Social Services and the Ministry of Health and Long Term Care, to provide residential supports or assisted living services to almost 125 people in close to 40 homes. In addition, it provides day and overnight respite services at 6 locations to another 50 adults who are medically fragile, including those who are ventilator dependent. Through their community involvement program at least 40 adults are supported to participate in individual and or shared leisure, volunteer and educational pursuits of their choice in the community. PHSS assists approximately 25 families with adult children living at home to manage their individualized funding in a wide variety of ways.

For 26 years PHSS has demonstrated visionary leadership and provided acclaimed support services of the highest quality. As an organization, it continues to grow as it responds to the needs of people and families in our community with flexibility and innovation.

PAR Process 2000-2006

In 2000, the PHSS Board of Directors created a Quality Outcomes for People Committee (QOPC) for accountability purposes. The Board and Management wanted to know whether the organization was fulfilling its promise and obligation to the people it supports. The QOPC decided to use Participatory Action Research (PAR) to evaluate outcomes. In contrast to more traditional forms of “research,” PAR is a pragmatic evaluation approach that emphasizes reflection and study; focuses on improvement and action; and involves people as participants in the study and change processes. PAR is a research method that is qualitative, quantitative and participative. It has as its twin goals the achievement of both action and research in the same evaluation method.

PAR Process 2007-2014

During this time period, we realized that although we had improved data collection, and met or exceeded all compliance and accountability standards, we needed to move the discussion to areas of quality regarding:

- the responsiveness of services
- meaningful change/support in people's lives
- resiliency and ability to adapt and overcome barriers
- inclusion in community beyond our physical presence
- creative problem solving
- a move from checklists to a sense of well-being, quality of experience, value and meaning.

We began a shift...how can we live our principles, reflect, and listen in a way that creates daily meaning for those supported, families, staff and community? We began asking *questions which would lead to a deeper inquiry and to a collaborative engagement to reflect on our principles...*

- Values
- Advocacy
- Enrichment
- Dignity
- Importance of family/friends
- Responsiveness

Current Environment

Board of Directors- Focused on Quality

A. Quality Assurance Committee

- Enlists people receiving support, families, and community members to be part of this committee
- Visits individuals and their families bi-monthly at their homes where support is provided to review/discuss service; and to establish relationships
- Oversees the bi-annual PAR process

B. Policy and Oversight Committee

- Reviews compliance reports quarterly at committees of the board
- Reviews Health and Safety, incident reports, and risk management reports
- Integrates PAR, and action plans into its strategic directions

Operational Response/Management Response – Focused on Quality

A. Identified Areas of Excellence (based on the PAR report of 2012/2013) and established team of staff, consumers, and family to work with these areas:

- Medical, Health and Wellness
- Challenging Behavior
- Self-Advocacy
- Leadership
- Communication/Augmentative communication
- FOCUS
- Meaningful Supports - Person Centered Planning, Families and Connector Group

B. Individuals and families participate in

- Hiring interviews
- Evaluations
- Family Gatherings
- Advocacy committee
- Committee/Board Membership inclusive of consumers/families
- Focus groups, surveys annually and part of strategic plan
- Staff and consumer training and orientation focus on quality

C. Compliance review

- Completes quarterly and annual compliance reports related to health /safety and risk management standards.

Overall, steps to create increased reciprocal dialogue and/or learning conversations which lead to more inclusive and focused problem-solving and an environment which reflects this shift.

III. Themes Resulting from the PAR Report as Identified by the Quality Assurance Committee

The 2015 PAR report emphasizes that *meaningful, person-focused supports drive quality experiences*. The report describes many areas of growth and offers items for action (See “Recommended Ideas for Action” in appendix A). The Quality Assurance Committee suggests there are numerous *themes* emerging from the 2015 PAR report, but the one overarching theme driving quality (see appendix B), from which all other themes stem is...

Enhancing Meaningful, Person-Focused Supports ~

The organization’s focus on meaningful, person-focused supports is part of the transition to a culture of providing supports to people in a manner that encourages full self-actualization, inclusion and participation at home, with their family and in the community. Findings in 2015 suggest an awareness of meaningful supports is increasingly growing and becoming embedded in the organizational culture. There are strong components within the organization that have built and spread the concepts and commitment to meaningful supports, such as:

- Person Centered Planning
- Creation of Areas of Excellence
- “Possibilities in Paint” Collaborative Art Studio
- Ongoing face-to-face, in-home interviews and visits with individuals and families by members of our Quality Assurance Committee (“mini-PARs”)
- Training and teaching events

The QA Committee suggests the following themes ensue from enhancing meaningful, person-focused supports:

1. PRESERVING WHAT IS SACRED

Participation House Support Services has historically provided accessible housing and support services that effectively address health and safety, personal care, shelter and security needs. These are met and addressed with a high degree of satisfaction. PHSS is exceptional in this area.

Continue the excellent work being done to maintain houses, accessibility and the ongoing efforts in adapting to individual changing needs.

Continue the creation of different living and funding options and opportunities for those we support and those with complex needs.

Review and adjust the eight existing Areas of Excellence (Leadership/ Medical, Health and Wellness/ FOCUS/ Families/Self-Advocacy/Challenging Behaviour/Communication/ Meaningful Supports) to reflect feedback from 2015 PAR report and respond to emerging themes.

2. COMMUNITY ENGAGEMENT

PHSS needs to cultivate meaningful community connections and engagement both individually and collectively. On an individual basis it includes the belief in full citizenship for everyone and works towards true community inclusion and valued social roles, one person at a time, as per their person-directed plan. We need to move beyond community presence to valued community participation and contribution. At an organizational level it involves collaborative, multi-layered work across sectors with our community partners to create options for full inclusion.

3. RELATIONSHIPS

We need to continue to develop and nurture relationships for the individuals we support with their families, friends and community members.

When people do not have family, we need to work with intention and creativity to think about support circles and the inclusion of volunteers in their lives.

At an organizational level, we will continue to build relationships, collaborations and partnerships in the community.

4. TECHNOLOGY

There is a need to expand and promote the targeted use of technology for a variety of purposes, both for individuals and the organization. This includes the increased use of various new technologies and social media for communication, promotion, outreach, education, information-sharing and other purposes.

5. ADVOCACY

PHSS needs to increase its efforts to support various kinds of advocacy; this will include self, individual and systemic. These efforts influence and promote positive change that's congruent with our vision and mission and also have meaning for the individual and their family. Stakeholders have indicated that it is important for the advocacy efforts to be directed at areas and issues that are important to them and result in meaningful change. This includes advocacy efforts for those who currently receive service from PHSS and their families; as well as those in the community waiting for service and their families.

6. ACCESSIBILITY

PHSS will continue to call for and work towards accessibility for all people within our organization and in the broader community. This includes access to physical buildings and public spaces as well as to generic and specialized supports services and community life.

7. FAMILY ENGAGEMENT

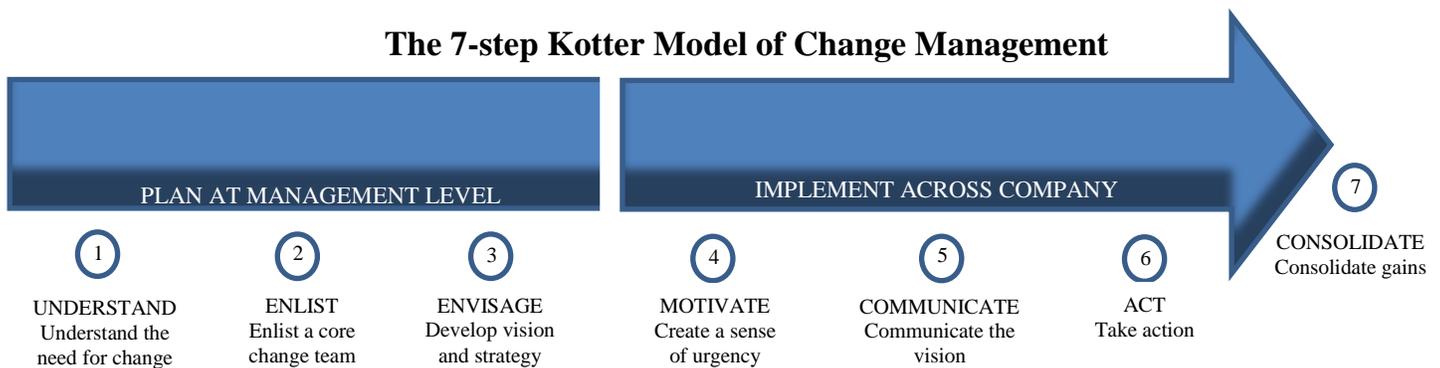
PHSS needs to expand efforts in family engagement with those who receive residential services (internal) and those who do not (external) for a variety of purposes such as social/fun, information-sharing, educational, supportive/mentoring.

Recommended Actions:

Create new Areas of Excellence as per identified themes

Use the Kotter model of change:

Establish and enlist stakeholders and champions for each core team; develop a vision and strategy for each Area; create action plans; communicate to all stakeholders; implement, evaluate, review and adjust



ll create a work do of l through actions, efforts and resources which stem from these guiding principles:

- ✚ We will value, support and encourage creativity
- ✚ We will leave our comfort zone and take risks when warranted
- ✚ We will build on passions where and when we find them
- ✚ We will disassemble barriers, one at a time, as we encounter them
- ✚ We will be solution-focused, problem-solvers
- ✚ We will be driven by an individualized and person-directed stance in all we do

IV. Next steps for PAR

Quality Assurance Committee

- This document will be reviewed and approved for presentation to the Board of Directors as the QA Committee's recommendation for follow-up to the 2015 PAR process.

After acceptance by the Board of Directors the QA Committee will:

- Create new Areas of Excellence, based on emergent themes, as the mechanism to develop core change teams by engaging and involving all stakeholders (consumers, families, staff and community members); develop visions and action plans for each team;
- Create a detailed overall operational action plan
- Create an internal communication plan (for participants and internal stakeholders)
- Provide further input to PHSS' strategic planning process

Board of Directors

- This document will be presented to the Board of Directors for acceptance and use to guide upcoming strategic and operational planning by PHSS.
- Determine communication to external stakeholders
- It will be communicated to external stakeholders

Appendix A

Vision Management Participatory Action Research Ideas for Action 2015

Recommended Ideas for Action

The PAR Committee discussed the Perspectives Report and identified the following ideas for action. Some *context* is provided for each, reflecting findings from the PAR process. These ideas for action have implications for the broader PHSS community. Most ideas need to be more fully developed so that management, staff, and the Board can implement them.

1. Facilitated person directed planning (PDP): *PHSS' facilitated PDP process has expanded the level of participation in dreaming and determining how individuals can define and achieve their goals. This represents a culture change for the agency and a great deal of progress has been made over the last three years. The Mini PAR process reinforces the value of this shift in planning approaches and organizational culture. The process helps monitor results.*

1.1 Idea for action: continue to employ Mini PAR process to reinforce the value of PDP, and support continued culture change and the participation of staff at all levels.

1.2 Idea for action: identify and analyze successes to date. Examine where and why the PDP process has been most successful – i.e. which individuals are receiving the best supports and what factors made a difference; is it about the level of staff support received, individual staff, access to vehicles or funding, or other?

1.3 Idea for action: celebrate progress to date to reinforce and expand awareness of individual accomplishments as a way of inspiring others about possibilities.

1.4 Idea for action: review evening and weekend schedules at some homes in response to issues raised in family survey concerning individuals' limited involvement in activities on evenings and weekends.

2. Family relationships: *the interviews highlighted that those individuals with actively involved family members may access a broader range of activities and opportunities. PHSS appreciates that connections to families and friends enrich the lives of individuals living at PHSS in a variety of ways. As parents, who are often the primary connection for individuals, age, the importance of strengthening connections with other family members (e.g. siblings, aunts, uncles, and cousins) and friends increases. How families are defined is changing, so a better understanding of how individuals and their families define 'family' will be important.*

2.1 Idea for action: explore and experiment with different ways of establishing, renewing and/or deepening connections with extended family members and friends.

- 3. Volunteers:** *a few individuals interviewed identified a need for one-on-one volunteers. Although PHSS posts volunteer opportunities on its website, finding an appropriate match may require actively reaching out beyond the PHSS community. Thanks to one staff member's networks, Possibilities in Paint has engaged a number of artist volunteers who value the opportunity to be a part of the project.*

3.1 Idea for action: use various communication tools (e.g. newsletters, social media) and PHSS staff and family networks to identify and reach out to relevant volunteers and promote the benefits of getting involved.
- 4. New technologies:** *PHSS has updated and expanded access to new technologies over the last few years. Homes are all equipped with computers, internet and Skype; the agency updated its website and is on Facebook. Some individuals have iPads and communication related apps. Others are blogging and/or have expressed interest in blogging. Platforms like Twitter and Yelp offer a way for individuals to share their experiences and lend their voice to public discussions about topics such as community accessibility. The potential of these new technologies has not been fully achieved among staff and individuals.*

4.1 Idea for action: identify one or more technology and social media 'champions' on staff who can assist the PHSS community in making better use of available technologies. Continue to identify new technology opportunities as they emerge.
- 5. Family connectedness and engagement:** *interviews and survey responses reinforce that families are busy and want/expect different things from PHSS events and communication. PHSS has experimented with different social and fundraising events, and many families do value these opportunities to connect. Some indicated that they might be interested in connecting for the purpose of learning – one family member proposed an annual family conference where family members could learn about funding changes, treatment, and from one another's experience.*

5.1 Idea for action: connector group could reach out to families to better understand their interests, skills and talents and what kinds of events they would value.

5.2 Idea for action: explore the concept and potential of family to family mentoring.
- 6. Individual and family advocacy:** *although much progress in developmental services over the years has been driven by families advocating individually and/or in groups, families that PHSS supports, who are relieved that their family member finally has support, often feel their advocacy work is done. Such families are often exhausted, while others may not define the work they've done over the years as advocacy. Some families receiving services reported they have supported or mentored other families on a one-on-one basis.*

At the individual level, individuals are interested in raising their voices about issues they experience, and PHSS has supported the Power to the People self-advocacy group. The group has struggled to influence some persistent municipal issues that impact those receiving support at PHSS. In contrast, PHSS' Family Resource Coordinator has successfully supported groups of families in advocating for funding for services such as overnight respite and the development of new housing.

The term advocacy has some negative connotations and opportunities to engage in influencing change and resolving issues in the broader community may need to be reframed – for individuals and for families with and without service. One specific issue identified during PAR interviews concerned the inaccessibility of the new YMCA facility pool due to an inadequate lift mechanism. This suggests there may be a gap in the understanding of accessibility considerations related to the design of public spaces and facilities. The Board may want to consider its role in relation to this work.

- 6.1 Idea for action:** partner with others to expand understanding of accessible design. This might include an accessibility test group (comprised of individuals at PHSS), a guide outlining what PHSS has learned, or in the longer term a consulting service.
- 6.2 Idea for action:** collaborate with YMCA to ensure that individuals with physical disabilities can use the pool in the new facility (e.g. PHSS might purchase or contribute to the cost of installing a lift). Board members might identify whether they have contacts on the YMCA board.
- 6.3 Idea for action:** support and stand beside Power to the People in their advocacy efforts – e.g. explore the role that families, the Board, and the Family Resource Coordinator might play in helping them amplify their voice and achieve their goals.

Conclusion

PHSS' PAR process engages individuals (50 to date), their families and extended community, agency staff and board to reflect on how the agency's work is impacting individuals' quality of life. Individuals are at the centre of PHSS' work. Most individuals who volunteered to be part of the process in 2015 seemed to enjoy the focus on their experience living at PHSS – they welcomed interviewers into their homes and lives. The process provides an opportunity to reinforce organizational values and assess the extent to which these are expressed throughout the agency's activities.

Recommendations from previous PAR processes have informed the strategic directions and goals outlined in PHSS' Strategic Plan. In 2015, the PAR process focused on three strategic goals identified in the 2012 Strategic Plan – i.e. enhancing meaningful supports, increasing family engagement and connectedness and supporting public advocacy by individuals and families.

The findings from 2015 suggest that the agency's focus on meaningful supports is becoming more fully embedded in organizational culture and that individuals are benefitting from help in articulating and realizing their goals and dreams. This support is most evident in the facilitated Person Directed Planning process which more actively engages individuals and their broader community in developing and implementing plans. The Mini PAR process has helped give these plans more prominence and importance by checking in on progress and assisting staff in finding creative solutions to address barriers.

PHSS has gradually expanded the ways that families connect with the agency and one another. Communication vehicles continue to evolve, and families of various generations have different expectations concerning communication media, content and frequency. This is also true of how families would like to connect with others in the PHSS community. While many enjoy and participate in social and fundraising events, some expressed interest in connecting for different purposes – e.g. to learn about broader issues such as funding that may impact their family member.

Public advocacy by individuals and families continues to be challenging for many who lack the time, energy and how-to knowledge. PHSS provides some staff support to the individual self-advocates involved in Power to the People, however the group has struggled to expand its membership and engage community organizations. Although most families are experienced in advocating on behalf of their family members, a smaller number have worked to advocate for more systemic changes. Despite this, families identified a variety of issues in the local community that they would like to see resolved. Reframing 'advocacy' (e.g. as 'solution building' or 'problem solving') and identifying specific issues might make it more attractive to family members. PHSS has been more successful in supporting groups of families who don't currently have access to services, thanks to the Community Resource Coordinator role.

Appendix B

Enhancing Meaningful Person-Focused Supports

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