

# CASE STUDIES FOR SOCIAL TRANSFORMATION THROUGH OCCUPATION

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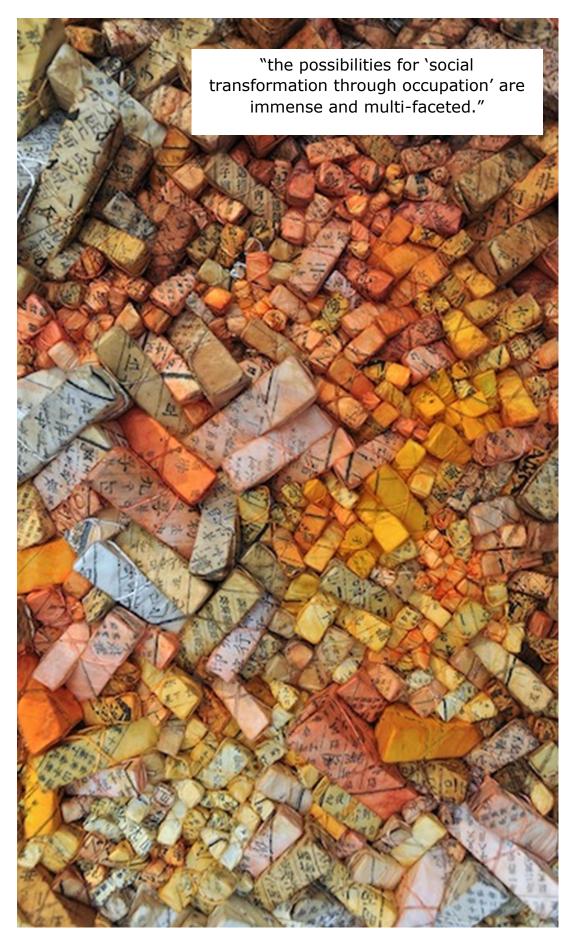
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through Occupation Network

With thanks to Ryan Lavalley for his contributions to the development of the text.

Image: Kwang Young Chun, Exhibition 'Aggregations'. Edinburgh 2015. Photo: Sarah Kantartzis







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# Part A.

# 1. Introduction

Within occupational therapy and occupational science, increasing concern regarding issues framed as occupational inequities and injustices have led to discussions regarding how to best address such issues and how occupation can be mobilized within such efforts (Farias & Laliberte Rudman, 2016; Galheigo, 2011; Guajardo & Mondaca, 2017; Pollard & Sakellariou, 2014). Globally, a heightened awareness of the implications of various socio-political factors and trends, such as the rise of neoliberalism, changing labour markets, migration, population aging, and climate change, has been linked to calls to further practices that draw upon occupation to address social and occupational inequities through social transformation (Farias & Laliberte Rudman, 2019b; Shann at al., 2018). As a group concerned with social transformation through occupation, the authors of this e-book, who are part of the International Social Transformation through Occupation Network (ISTTON), are

"committed to gathering information and creating pathways towards actions to tackle such inequalities from an occupation-based perspective [and] to bringing together diverse theoretical perspectives and practices to move social transformation through occupation forward." (Laliberte Rudman et al., 2018, p2)

The e-book is one part of our efforts to contribute to the further development of 'social transformation through occupation'. The cases in the e-book were developed within the context of a research study carried out with support from ENOTHE (European Network of Occupational Therapy in Higher Education). This e-book shares the exemplar case studies generated through this research project, providing ideas for how such case studies can be used in education and practice. It also creates a space and mechanism for further sharing of exemplars. Projects which address social transformation through occupation must be responsive to local contexts, and are shaped within the particularities of the forces at play in local contexts. As such, these exemplars cannot necessarily be applied to other situations without considering their fit with local circumstances and needs. Often there are complex community relations, different policies and legislation, administrative procedures and cultural norms, and any work must take account of all these. While the exemplars may offer guidance, they are not presented as literal models, or how-to manuals, which can be transferred to other situations.

Within this e-book, the term 'social transformation through occupation' is used broadly to refer to various approaches that focus on using occupation as a means to restructure practices, systems and structures, so as to ameliorate occupational and social inequities. Aligned with the UNESCO conceptualization of social



transformation, the term social transformation "incorporates the change of existing parameters of a societal system, including technological, economic, political and cultural restructuring". (UNESCO <a href="http://www.unesco.org/new/en/social-and-human-sciences/themes/international-migration/glossary/social-transformation/">http://www.unesco.org/new/en/social-and-human-sciences/themes/international-migration/glossary/social-transformation/</a>).

Starting from the premise that 'social transformation through occupation' is not a singular approach to practice, this e-book does not aim to offer one conceptualization of this approach or a set of standard guidelines for its enactment. Rather, this e-book contains case examples that demonstrate that the possibilities for 'social transformation through occupation' are immense and multifaceted. Each of the cases integrated into this e-book tells a narrative which illustrates a particular trajectory of development, beginning with everyday problems related to occupational participation. This e-book is a beginning response to an identified need, articulated in various workshops facilitated by the ISTTON, to provide 'real life' cases that extend beyond using occupation to promote change at the individual level towards using occupation as a means to work towards social transformation. In other words, occupation may be thought about less as something that an individual does or aims to do, but rather as 'things we do together' that have the potential to initiate or to contribute to processes of transformation. These cases encompass diverse ways of thinking about, mobilizing and addressing occupation, and can be used within educational and practice contexts to further spark diverse ways of thinking about the connection between occupation and social transformation.

To direct the selection and development of case exemplars for this e-book, we identified examples that employed occupation as a means to enact changes in social practices, systems and structures so as to promote positive outcomes at a community or societal level, such as increased social cohesion, expanded occupational opportunities, and combatting forms of discrimination. This approach to selecting exemplars is aligned with the broad conceptualization of 'social transformation through occupation' that emerged from a recent critical dialogical study conducted with five occupational therapists and/or occupational therapy educators located in different parts of the world who were using occupation-based approaches in order to enact social changes (Farias & Laliberte Rudman, 2019a). This study found that these participants were drawing upon key principles and practices associated with broader models of social transformation, particularly those associated with participatory, emancipatory and community development approaches. Aligned with these types of approaches, participants emphasized the need to:

- span a continuum from individual lives to political systems;
- incorporate critical examination of power and positionality;
- engage critical theoretical frameworks; and,
- build collaborative partnerships across diverse groups.



Building on these foundational elements, participants strove to enact an occupational lens in their transformative work; for example, they sought to:

- question taken-for-granted aspects of societies that produce and perpetuate occupational inequities;
- promote critical awareness of the societal causes and implications of occupational inequities; and,
- employ occupation as a means for "disrupting the broader systems that extend beyond individuals' control and cause injustices" (Farias & Laliberte Rudman, 2019a, p.1).

Although the use of occupation to enact social transformation to ameliorate issues framed as occupational and social inequities is embedded within the historical roots of occupational therapy, and practice approaches aimed at social transformation have been implemented in contexts such as South America and South Africa, continuing to move forward with social transformation through occupation requires on-going dialogue regarding its theoretical foundations, practical strategies, and how it can be supported through education (Laliberte Rudman et al., 2018). Creating spaces to share and discuss how 'social transformation through occupation' is currently being conceptualized and enacted is key to enhancing the capacity of occupational therapists and scientists to analyse and address the socio-political forces working against occupation as a human right (Sakellariou & Pollard, 2017).

Extending beyond forms of occupational therapy practice that focus on working with individuals facing challenges to occupation to employing occupation as a means to enact social transformation raises many important questions such as: How can occupation be mobilized as a means to enact social transformation? How can social transformation efforts be directed towards altering practices, discourses, systems and structures that shape and perpetuate occupational inequities? What theoretical frameworks and practice approaches can be taken up to enact social transformation through occupation? How can educators best prepare students for enacting social transformation through occupation? We hope that the cases in this e-book provide a launching pad for such dialogue within educational settings and support occupational therapists wishing to develop their practice into these areas (see chapter 2).

Furthermore, as detailed in the next section of the e-book, we hope to further foster diverse ways of thinking and doing 'social transformation through occupation' through on-going integration of new case examples into this e-book (see chapter 3).



# 2. Overview of cases and potential uses

The cases included within this e-book thus far encompass a diverse range of practices, such as grassroots community initiatives, participatory research, community-university partnerships, and not-for-profit initiatives, that centre occupation within efforts to enact sustainable systemic and structural changes that address occupational inequities. Within many of these cases, the described forms of practice embody a commitment to working with collectives experiencing marginalization, for example, within health care policy, within social relations in their communities, or from occupational opportunities. As displayed in the cases, these forms of practice often involve working with key stakeholders across sectors. While such practices share commonalities with many developed across a range of disciplines and organisations, the centering of occupation in these initiatives supports the core principles of occupational therapy and occupational science around the power of occupation to shape both individual and societal transformation. The cases shared within this e-book display that such practices can mobilize occupation, often as a collective form of 'doing together', as a means for transformation, and/or target occupational inequities within identified outcomes of transformation.

The cases included address social transformation at various levels and in diverse contexts; for example, changing social relations within specific communities, transforming organizational practices, and informing regional policy changes. The cases also address a range of social issues of relevance to occupational therapy, such as social exclusion of particular collectives, ageism, racism, homelessness and poverty. Looking across the cases, they integrate 'doing together', ranging from individuals coming together to learn and participate in a particular occupation, such as football or knitting, to individuals intentionally engaging in an occupation collectively, such as building a community garden or an advocacy campaign. The cases illustrate ways that such 'doing together' can become vehicles for the germination of empowerment, capacity building, and consciousness raising; launchpads for new connections and changed social relations; and the regeneration of spaces for living - for occupations - in cities and in people's everyday lives.

In terms of targeting occupation as an outcome of social transformation, the cases present diverse examples of connecting social transformation to expanding occupational opportunities for collectives, such as engagement in sport, gardening or the arts. These cases also address aims related to transforming taken-forgranted beliefs and practices related to what types of occupations are seen as ideal, appropriate and possible for whom and, in turn, who has access to what types of occupation. Underlying assumptions tying the cases together, sometimes explicitly articulated and at other times implicit, are that the transformative potential of occupation can be sparked through doing together, and that opening



up spaces for occupational opportunities is an important target for, and tool of, social transformation through occupation.

As with any form of practice, good intentions to embark on a social transformation initiative¹ do not automatically result in the doing of good (Pollard and Sakellariou, 2009). As such, these cases also highlight the need for on-going critical reflexivity regarding the assumptions and values guiding and enacted through an initiative, for example, attending to how 'positive' transformation is being defined, who is defining it, and how broader contextual forces may shape the initiative in unintended ways (Farias & Laliberte Rudman, 2019a). These cases are not presented to provide 'ideal' exemplars that detail the only or the 'best' ways to think about and do 'social transformation through occupation'; indeed, a recipe book approach is at odds with this form of practice given its participatory, relational and situated nature. Rather these cases were selected to represent diverse possibilities, in terms of actors, issues, methods, and other features, that sought to genuinely attend to key issues that require on-going attention within efforts aimed at social transformation through occupation.

We invite readers to engage with these cases within educational and practice contexts as a means to be critically reflexive regarding how to think about, engage with and continue to develop 'social transformation through occupation'. When utilising these case studies various philosophical, theoretical, political, practical and methodological issues could be examined. Below, we list examples of topics and issues pertaining to the role of occupation and approach to social transformation that can be used to facilitate critical dialogue and reflexivity on the cases. For example:

#### The Role of Occupation

- The power of occupation for social transformation; the particular characteristics and 'shape' of occupations that facilitate such processes
- Ways occupation is part of relation-building and capacity building
- Ways occupation is mobilized as a means to bring about social transformation and/or integrated in processes of change
- Methods/theories/professional reasoning used in the process of social transformation through occupation
- How opportunities for occupations, and the form and performance of occupations, are shaped by existing power structures

#### Considerations for the Approach

 How social transformation efforts are directed towards altering practices, discourses, systems and structures that shape and perpetuate occupational inequities

<sup>&</sup>lt;sup>1</sup> The term 'initiative(s) is used throughout this to indicate a wide range of projects, practices, movements, programmes, services etc that are aiming at social transformation based on occupation.



- Challenges to the sustainability of social transformation, and various ways of addressing these challenges
- Ethical principles and practices that appear vital in these approaches
- Ways of implementing these practices that avoid enacting 'power over' partners who are often socially positioned as 'marginal', and of genuinely working towards more equitable power relations
- Theoretical perspectives to frame and inform such work, and how these might evolve out of doing such work
- Critical consciousness raising amongst participants and stakeholders and responsibilities that evolve out of raising such awareness
- Riskiness of these practices for various types of participants, and how such risks can be managed
- Tensions that can arise given the evolving, participatory nature of these practices within political and funding contexts that may expect certainty in questions, processes and intended outcomes, and approaches to negotiating such tensions
- The centrality of partnerships, and potential ways forward and challenges associated with striving to create equitable, authentic and sustainable partnerships
- Required resources, and approaches to identify and mobilize these

We invite all those using the cases to send us your feedback with your ideas for how the cases may be used in education and practice and suggestions for further development of this material. Please contact us at <a href="mailto:isttonetwork@gmail.com">isttonetwork@gmail.com</a>.



# 3. Developing new cases; contributing to this resource

We invite you to contribute further cases to this e-book. In this section we outline a process for this based on our own development of the original cases. This process includes the following stages: Identifying the case; developing the case; submitting the case for inclusion in this e-book. While we will present some guidelines (proposed interview questions and guidelines for presenting your case) we recognize that each initiative and the people involved in them are unique and both interviews and case presentations will be undertaken to illuminate that uniqueness. Therefore, the proposed interview questions are intended to act as suggestions and prompts rather than rigid guidelines. Likewise, the presentation of the case should be organised in a way that captures the key points and central issues.

#### Identifying a case

A case is developed either from an interview with a participant or from your own experience with an initiative (see further comment below on this latter option). A participant is someone who has significant involvement in the initiative. The case can be based on a wide variety of initiatives, for example: time limited to ongoing; with or without occupational therapy involvement; occurring in community, practice, research, policy, educational or other contexts; developing formally or informally, within or outside existing systems and structures. It must incorporate occupation although it may not be named as such by the participants. It should be achieving some form of social transformation; it should be developed with an expressed intention to alter for the benefit of those involved the structural conditions of people's everyday lives or there is recognition that this is occurring although perhaps not the original aim of the initiative.

The interviewee can be from any country of the world and interviews may be undertaken by skype if face to face communication is not possible. Publication of the case can be in any language although an English translation is also required.

The initiative that will be the focus of the case should be well-developed or completed (within the last three years). The interviewee's involvement in it should be significant and/or they should have extensive knowledge of it. The initiative should be occupation-focused, and the person is able to discuss this. However, it is not required that an occupational therapist or occupational scientist is involved in it or is the interviewee.

Writing a case from your own experience: While we recommend that undertaking an interview is a particularly useful way of understanding the processes and impact of a particular initiative, even if we are also involved in it, there will be circumstances where you wish, or are only able, to provide information directly. If possible, please hold informal discussions with other members of the initiative as you develop the case and consider the interview questions in Appendix 1. Please



ensure that you have the required permission of others involved to move forward in writing up the case. See Case 6 as an example of a case developed without interviews by the coordinator of the initiative.

#### Process of developing the case

If the development of the case involves an interview, the person who is interviewed should be able to speak for the initiative. Ideally the interview and the development of the case should be a collaborative process and the person interviewed should be the co-author of the published case. This role should be discussed with them prior to the interview.

A recorded interview should be made. In Appendix 1 we present the interview schedule that we followed during the interviews. While this may vary from case to case, we suggest that this example presents the key elements to be considered. Following the interview, the case can be constructed, following the guidelines below.

The final draft of the case should be reviewed by the person interviewed and if they wish by others involved in the initiative. A representative of the initiative (who may be the person interviewed), must agree to publication of the case in writing. Please see below further details of how your case may be presented.

Please take careful consideration of ethical issues when selecting an initiative, undertaking any interviews and in developing a written case, particularly issues of power and the re-enforcement or re-production of inequalities and injustices. It is also the author's responsibility to ensure they have followed any guidelines that exist in their context that involve writing up and publicly circulating the case, such as ethical guidelines, authorship guidelines or institutional policies, as relevant.

#### Submitting the case for inclusion in this e-book

The final draft will be reviewed by two members of the group and/or organising members of ISTTON (International Social Transformation Through Occupation Network) prior to publication. This is to ensure that the case addresses the key issues and processes of social transformation through occupation, and that any context-specific information or terms are explained for a global audience. It will also ensure that the case adheres to the ethical principles supported by the group. The reviewers will not undertake a review of language. You are also welcome to contact the group for advice or to discuss your proposed case from an initial stage. Please submit your case for review and inclusion in this e-book to the International Social Transformation through Occupation Network at: isttonetwork@gmail.com.

#### Case study content

Below we outline what we consider to be the expected content to be addressed in each case and suggestions for headings. In cases where an interview or interviews



have been conducted, we strongly encourage authors to integrate direct quotes as relevant and if there is permission from the persons interviewed to do so.

Name of initiative. (provide website details if available)

**Authors.** (with affiliations)

#### Introduction.

- A brief introduction that establishes the aim of or the lens applied for writing up the case; this lens/aim will then organize how the case is described (for example, "this case attends to a non-occupational therapy organization that uses occupation as a means for social transformation", or "this case addresses an example of how social transformation initiatives are integrated into occupational therapy education").
- Situate the case in its broader context (e.g. national context, type of sector case is embedded in, etc.).

#### Broad description or overview of the initiative.

- Describe the vision and/or key purposes/aims/objectives of the initiative.
- Describe the more specific context: e.g., details of the community/area; historical background relevant to origins of the initiative, the people who are involved and different levels of involvement.

#### Who is involved and how they work together.

- Who are the key players in the initiative? (e.g. individuals, organizations, etc). How have these key players changed/remained the same over time?
- Who is the initiative designed to work for/with, and how is it organised with and around these people or their needs. For example, is it collective or participatory, does it have formal organisational features such as a charitable status or social enterprise, or does it have a more informal structure – how does this relate to aims, purpose and context.
- What are the relationships with other organisations (macro/meso/micro level)? Are there partnerships or connections with similar organisations or groups? Are there connections with agencies or input from professional workers or organisations?
- How do participants/members work together (model or approach to facilitation, co-operation, or shared membership)?



#### Processes of transformation.

- Outline how the initiative began and subsequent developments over time, capture the process including expected developments as well as non-linear aspects (e.g. new opportunities that arose, new types of activities incorporated, etc.).
- What has the initiative achieved in terms of social transformation, and/or what can it anticipate having achieved? This may be an inter-relation of personal and societal transformation (attitudinal and structural).

# Occupation and processes of transformation.

 Address explicitly how 'occupation' is incorporated/addressed in this initiative, and its processes and everyday practices (for example, identify aspects which facilitate participants/members in active doing, or contributions through action to the outcomes of the initiative).

# Theory/practice links.

- Identify the theoretical basis, key guiding principles or assumptions.
- How and when were theoretical frameworks and/or principles identified and how widely are they shared amongst members/participants?
- Have theoretical ideas evolved out of the initiative?

#### **Key resources and barriers.**

- What and who are described as the key resources and facilitators throughout various phases of the initiative? (e.g. funding, policy initiative, key people, media campaign, availability of space, etc.).
- What have been key barriers experienced throughout the various stages of the initiative and how were these addressed?

#### Sustainability and continuity.

 Is the initiative completed or on-going? Is it anticipated that the initiative will end or are there plans for continuity, further phases of development, evaluation and review?

#### Best Tip.

- What advice do you have for others beginning similar initiatives?



#### References. Part A.

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# Part B

# The Cases

- 1. Street Soccer Scotland, UK. Andy Hook and Sarah Kantartzis
- 2. Exercising Citizenship in an Ageist Society, Canada. Barry Trentham, Sheila Neysmith and Debbie Laliberte Rudman
- 3. Langa Cheshire Home Community Development Practice site, South Africa. Roshan Galvaan, Leigh Ann Richards and Hanneke van Bruggen
- 4. Internationale StadtteilGärten Hannover e.V. (International City District Gardens Hanover), Germany. Eberhard Irion and Sandra Schiller
- 5. Knit and Natter, Barnsley, UK. Claire Craig
- 6. Sent x 100: Art and culture for wellbeing and social participation, Spain. Salvador Simó Algado, Jèssica Garrido and Penélope Aguilera



#### Street Soccer Scotland

Andy Hook<sup>1</sup> and Sarah Kantartzis<sup>2</sup>

<sup>1</sup> Head of Programmes, Street Soccer Scotland.

<sup>2</sup>Queen Margaret University, Edinburgh, UK.

#### Introduction to the case

This case provides an example of a social enterprise, without occupational therapy involvement, that uses occupation and specifically football, as a foundation for individual and social change for people who are homeless or facing challenging circumstances. The organisation, Street Soccer Scotland (SSS) is located in Scotland, UK, and introduces itself on its website as follows:

"Founded in 2009, Street Soccer Scotland is a social enterprise which uses football inspired training and personal development as a medium to empower people who are affected by social exclusion, to make positive changes in their lives." (www.streetsoccerscotland.org)

While the focus of the organisation is primarily on the individual and change for each person, the organisation is also involved in preventative programmes in communities and organisations, recognising the ongoing impact of a person's successful change on their family and as a role model for others. The ongoing media coverage of the activities of the organisation as well as of the Homeless World Cup with which it is involved, has increased public awareness of the nature and extent of homelessness in Scotland. Stories of the individual change experienced by people involved in the programmes of SSS are available on their website, while this case provides a broad view of the organisation, its programmes and its understandings of change.

#### **Overview of Street Soccer Scotland**

Since its establishment in 2009 the organisation has been very successful, developing various programmes in a number of cities in Scotland, attracting people who are socially dis-engaged whether through homelessness, in rehabilitation following, for example, drug use, ex-offenders, or mental health issues. More recently the organisation is also working with younger people growing up in deprived areas and also those in transition from prisons and young offender units, aiming at early intervention and preventative work.



The foundations of the organisation and its programmes are to be found in the Homeless World Cup. For some years the Big Issue [the magazine sold by homeless people throughout the UK] in Scotland provided the players for the Scottish team to go to the Homeless World Cup. One of the players in the Scottish Homeless World Cup team in 2003 was David Duke who then managed the winning team in 2007. Following this win David began discussions about how there was no ongoing project to support the players either before or after the event. He met up with Andy Hook who was Director of Football for the Homeless World Cup, and Mel Young, the President of the Homeless World Cup. They discussed setting up a programme for engaging with people who were homeless or facing challenging circumstances that would run for 52 weeks of the year.

At that point David Duke "took the leap of faith" and in 2009 set up Street Soccer Scotland (SSS) as a social enterprise, supported by various organisations and charities.

The initial programme was established in Edinburgh and Glasgow (largest cities in Scotland) with free drop-in football sessions for anyone (not only the homeless) who wanted to take part. Over the years the project has expanded to other Scottish cities and towns - Dundee, Aberdeen, Kilmarnock, Paisley and Greenock. Each city or town may have more than one drop-in centre, and each runs a programme for two hours, two to four times a week. Men and women over the age of 16 can take part, and while numbers vary, up to 40 people may attend each session. Each session is organised according to the numbers attending but everyone will get a chance to play football. The programme is advertised in hostels, recovery units etc, while a recent study has shown that 49% of people attending hear about the programme by word of mouth.

#### Who is involved and how do they work together?

David Duke has been throughout an inspirational ambassador for sport and social change, both within SSS as CEO of the organisation and beyond in related work. In recognition of his work he was awarded an MBE (Member of the British Empire medal) in 2018. Andy Hook became an employee of Street Soccer Scotland and continues to work for the organisation. Andy Hook also works internationally, particularly in England, but also India, Nepal and Romania developing and supporting similar initiatives.

SSS is formally organised as a social enterprise. The central offices are located in Edinburgh, UK. Central office staff include the founder of SSS and CEO David Duke, his assistant (because of David's involvement in numerous other activities and social enterprises), and four staff. These staff include Andy Hook who is Head of Programmes, and three who are responsible for the following areas: 1) Governance and Administration, 2) Marketing and Public Relations, 3) Grants and



Foundations. As a social enterprise SSS is entirely dependent on external funding and support (further details will be presented later).

Beyond this core management team, each city where programmes are run has one or more coordinators. They have a variety of backgrounds; some have come through the programme as players, others include a former professional football player and a care worker. In addition, the work of the programmes is supported by about 40 volunteers, again, many of them came to the programme as players, while others have a range of backgrounds, for example, in football coaching.

The drop-in sessions are open to anyone who wishes to attend over the age of 16. These sessions are primarily aimed at engaging with people who are homeless, attending recovery units or facing multiple issues in their lives. No expectations or time limits are placed on those attending sessions. There is a minimum of registration required, including name and emergency phone number. More information will be obtained as the person becomes comfortable to provide it. Each session is developed around the needs of the particular people attending that session. The organisation has developed new activities and programmes over the years in a response to participants' changing needs.

The development of new programmes has been undertaken with a number of different partners. These include with Edinburgh College and Napier University in the development and delivery of educational programmes, with several Scottish Prisons and Young Offenders Units, and with local town councils around the provision of programmes.

SSS also develops links with interested organisations (e.g. Universities) to develop opportunities for increased awareness and support of their work (e.g. through football games with students; student research projects).

SSS has developed a largely informal network with the public services that are used or may offer support to the players. These include services and organisations working with similar populations and issues, for example, related, to housing, employability, youth work, rehabilitation. SSS has been invited to take part in policy development meetings with service organisations.

#### **Processes of transformation**

A core characteristic of SSS is its ability to offer ongoing support to players over extended periods of time and the development of new programmes to support their needs through their process of change. This is based on the core vision of SSS around the potential of each person for change and the importance of hope, despite the difficult and complex circumstances of their lives.

This longitudinal and flexible approach to change and support for that has led to the development of new initiatives and programmes in a responsive way. For



example, an early development was the Football Works programme. This was developed in partnership with Edinburgh College for those players who through attending the drop-in sessions had begun to gain a structure in their lives, to feel part of something, and who were looking for something more. Recognising that existing coaching and educational courses were not fitting the needs of their players, SSS designed a football-themed education course with a combination of activities, running two days a week for eight weeks, held in the various drop-in centres. In the morning, activities included the participants talking about football, watching videos, reading reports, and beginning to write about their own experiences in football (for example their favourite club or football match they had seen), receiving feedback on this, and thereby creating their own learning portfolio. In the afternoon they went out onto the football pitch and learnt about coaching and planning sessions. The course culminated in the participants planning and delivering a one-day football session with younger people. completion of the eight weeks the participants had completed two portfolios on the basis of which the college awarded them an SQA (Scottish Qualifications Authority) in 'Communication' and an SQA in 'Working with Others'. The programme enabled the players to learn through doing and to engage in a further range of activities.

SSS is responsive not only to the needs of the players, but also to external, structural changes. For example, currently the Football Works programme is being re-developed. This is due to changes in the way the government Department of Work and Pensions organises its Work Programme, which many of the players are required to attend. Because of this the players are unable to commit to attending the programme two full days a week. As a result, the programme is being redeveloped in collaboration with Napier University to create a modular programme (beginning in 2018) that will allow more flexibility, while also fitting with the Scottish Credit and Qualifications Framework (SCQF).

With this ongoing commitment to offer players further opportunities as they develop confidence and skills, a further programme was developed. As players progressed (either through the drop-in sessions and /or the Football Works programme) many wanted to give back to the community and become more active in soccer coaching. However, it was seen that they were not ready to run a football club or team because of the multiple organisational elements involved. With funding provided by the Scottish TV Appeal, SSS were able to set up Street Soccer For Change (Street Soccer FC). This programme added a new element to the work of SSS as it was developed with the aim of providing free football to children aged 10-16, in areas of multiple deprivation. Clubs have been set up in three or four areas of Edinburgh and Glasgow, and also in Dundee and Aberdeen. The sessions are run in various community centres located in the specific targeted areas. Sessions are usually held in the early evening. In Edinburgh, where there is no school on Friday afternoons, sessions are organised then, as it is seen to be a time when "kids get involved in daft things." The sessions are planned and delivered



by volunteers from SSS and graduates of the Football Works programmes, offering them opportunities to become more engaged and to gain experience in planning sessions. However, it is also recognised how they act as peer mentors to the children; in many cases, the volunteers have been in the same position as the children, they know what they are going through, and a bond begins to grow. The children who attend are usually those who cannot afford to, or due to their behaviour have been excluded from, attending other clubs. As young people progress through the programme, some have continued in education, have "turned their lives around", and so demonstrated to the younger players, their parents and the wider community that change is possible.

As well as the drop-in sessions for adults and children in towns and cities throughout Scotland, SSS organises regular local and national soccer tournaments. This gives the opportunity for those players who want to develop their football skills and to take part in a competitive match to do so, as well as bringing together different communities and groups. Matches may be between different SSS teams from all over Scotland and the north of England, or with teams made up of students, prison officers etc. SSS continues its close relationship with the Homeless World Cup, providing teams for the male and female tournaments. For this, players who fit the criteria for taking part are identified through the dropin sessions and are supported in their training and participation.

SSS continues to evolve, not only in response to players and local needs, but also to the particular skills and networks of the coordinators. One example is in Edinburgh, where a weekly session for people with additional support needs (e.g. autism, ADHD, minor physical difficulties, mental health issues) has developed due to the previous employment of one coordinator as a carer. People attend this session only following referral from services.

Another example is the development of drop-in sessions for new players. These were established when it was seen that some people initially find it extremely difficult to work in a group and need extra support and preparation before joining the regular drop-in sessions.

Specific work has also focused on the needs of women players. Although the drop-in sessions have always been open to men and women, it was seen that many women were not comfortable 'kicking a ball about' in a public space. This has been tackled in various way, and currently a programme for women (Street 45) is being developed, which involves 45 minutes of personal development activities and 45 minutes of sport. Street 45 is in its early stages, but participation has increased from 16 to 41 women in the first few months.

SSS may be the only service or organisation the person is involved where they can have an ongoing relationship over a long period of time and with which they can discuss all of their issues. The coaches and staff of SSS can get to know each person over several years, as an individual with complex issues and potential. SSS



is now in its 10th year and as former players engage with the programme as volunteers their lived experiences becomes part of the story of the programme. All the programmes and those under development follow a similar philosophy, with soccer at core.

#### **Evaluation**

In general, SSS considers it difficult to demonstrate the work that goes into helping people change. Although the ultimate aim is to help people out of homelessness, it is seen that it is not useful to measure change only in terms of whether the players have established homes or not. Obtaining and maintaining a home is only possible at the end of a very long process of change, often over many years, which will enable the person to be ready for that, including having built the confidence and skills to run a home.

Although it is difficult to demonstrate and evaluate these changes, a number of methods are used to try to capture the processes and outcomes of the various programmes. These are aimed at attracting and maintaining sponsors, but also to maintain a high profile with the general public. Historically case studies have been the primary way to illustrate individual, positive stories of change. Examples of case studies, with videos, are available on the website: www.streetsoccerscotland.org.

More recently there has been attempts to access personal change in more depth. Surveys have been completed, for example, of people taking part in the Football Works programme, and in one programme run in a prison. Currently an in-depth census is underway of all players, which will be analysed by a company undertaking statistical analysis on a pro bono basis.

#### **Occupation: Processes of change**

Playing football is at the core of the work of SSS. The original group of people that founded SSS came together through their involvement in football, whether through the personal experience of transformation through engagement in football and the Homeless World Cup, or through many years of coaching football players. The understanding of the potential of football to promote change is rich and multi-layered;

"35% is about football, the rest is about building trust, confidence, selfesteem and then work on communication – all the soft skills the players tend to lack."

That football is a team sport is important. Most players are isolated when they first join the sessions, but



"football is structured, there are instructions, football requires trust to pass the ball to someone else and for them to pass it back."

As they play, over several sessions trust builds through playing football, without questions and without judgement on their life circumstances. Football is the starting point. The team sport environment helps to break down barriers and build confidence. To play football you have to be able to trust other players, to relate to others, and to tolerate other player's different skills and abilities.

Helping the players see their change is one of the key things the programme offers. Change is demonstrated in what players are able to do and begins with football. A player may move from the first sessions where they may just say 'hi' and play, to the next sessions where they may say 'hi' to the coach and talk to other players', to a session where they say, 'I'll pick a team today' and act as captain. The coaches are able then, if a player is having a bad day, to point out the changes they have made; the majority of players need help to see that change is happening.

It is also understood that there is no time limit on how long change will take and that no-one knows how long it will take someone to change. Through football SSS can provide a whole range of ongoing opportunities (occupations) through its various programmes for players to have new experiences, to develop skills and confidence. These range from 'knocking a ball about' to playing in matches, to learning to plan matches and to coach others, to becoming a volunteer with the programme. Some may become part of the Scottish team for the Homeless World Cup.

Knowledge of 'what works' can be seen in the description of how a new player comes to engage with the drop-in sessions. When someone first comes nothing is asked about their background, a name and emergency phone number is the only information requested. They are just encouraged: "do you want to play football? Then on you go". It is seen to be important that

"we don't pigeonhole anyone, we don't stigmatise, we are not concerned about their background."

After a few sessions as the player begins to build trust in the volunteers and coaches they will begin to talk and more will be learnt around their background. Then the coaches can ask – 'how can we help you?' There may be problems with housing or with benefits, for example. At that point the coaches begin to draw on their networks to help signpost services to people. While the long-term goal may be for players to have a home and perhaps to find employment, it is understood that players need structure and organisational skills, education, to build their confidence, before they can deal with a home.

The environment of the drop-in sessions is important. Coaches need to have further skills than those required for traditional coaching, and the sessions are not



run as traditional coaching sessions. They need to pick up on body language and the mood of players when they come in. They are non-judgmental and often share similar experiences to the players. Boundaries are clear and occasionally a player may be asked not to come for a week or two if 'they have overstepped the mark' [behave in an unacceptable way]. However, the ongoing support is also important, so that people can 'try' new things and come back for support and discussion if it does not work out. The drop-in sessions, the coaches and volunteers may be one of the few stable conditions in someone's life over several years.

In terms of wider change, the opportunity for the general public to attend the various tournaments and to see homeless people in a new way is very important; the players begin to become 'little heroes' for the community. From the children's programmes, as some of the players become young adults and begin to volunteer with the programme, it is seen that they are modelling the potential of change for other young people.

#### **Funding and support**

Street Soccer Scotland is entirely dependent on external sources of funding and support. Looking for on-going support is a continual process. Since its founding a number of partners have provided long-term, substantial, support:

Powerleague (a provider of 5-a-side pitches throughout the UK) was the initial partner. With 5-a-side football pitches that were largely unused during the day, they saw potential in becoming a community partner and named SSS as their charity of choice. This provided the space for practices and also for meetings in rooms on the same sites. Other centres, particularly in the deprived areas of cities, also offer the use of pitches free of charge, following extensive networking about the purpose of the programmes.

Edinburgh College was formally a partner, and currently Napier University in Edinburgh, are involved in the development of the Football Works programme, awarding educational qualifications. Research programmes are underway with Queen Margaret University, Edinburgh and the University of the Western Scotland.

Scottish Television (STV) provides funding for Street Soccer for Change (SSFC) programme. SSS was awarded Legacy Funding by the Scottish government following the Commonwealth Games held in Glasgow in 2014. Other sponsors include a number of Scottish corporations including: The Royal Bank of Scotland, Microsoft, Scotch Beef and Contagious.

#### Sustainability and continuity

SSS is continuing to develop and expand. Ongoing work is required to identify funding opportunities and to develop successful bids for these, while evidence of



positive outcomes is required to support these. These are required not only to support the foundational work of the organisation, the drop-in sessions, but also the new and developing programmes.

With the experience gained over the years there is understanding of some of the routes that lead to homelessness and complex problems, and new programmes are planned that will address some of these. For example, a census of SSS players completed in 2017 indicated that 11% of the players had been in care (either in foster care or children's homes) and therefore this group of young people is considered at high risk as they move into adulthood. Plans are underway to develop future programmes with children in care with this group. Supporting offenders as they leave prison is also seen as an important point of intervention. A 6-week pilot programme has been developed with one of the Scottish prisons, with a second programme being planned with another. Both aim to offer a footballbased programme that the players can engage in while in prison, with the hope that by recognising what the programme offers and offering a face they can recognise, that when they are released the offender will continue their involvement with SSS. Pilot programmes are also underway with two secure units for youth in Glasgow. The aims are similar to the previous programme; helping the young people make relationships with people who are not seen as authority figures, that they can engage with as adults, with the hope that on release they will continue their engagement with the programme.

# **Challenges**

Ongoing funding for recruitment, training and development is a continual challenge for the organisation. The relationship with Powerleague and other centres providing pitches without charge is vital. However, further funding would facilitate numerous activities, for example, there is the need for more staff on the ground at the drop-in sessions to be able to deal with more of the issues which the players bring for discussion and guidance, especially if there are 30 or 40 players at a session. A qualified professional in each city (with knowledge and experience of the broader social issues), supporting the drop-in sessions, would also be extremely useful.

#### **Best tip**

Keep it simple and don't ask questions. Welcome everyone in and build it from there.



# Exercising Citizenship in an Ageist Society, Canada

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#### **Introduction to the Case**

This case describes a time-bound participatory action research (PAR) project, titled 'Exercising Citizenship in an Ageist Society', completed over a 2-year period with a pre-existing senior citizen's advocacy group called Care Watch. Care Watch is a non-profit, non-charity political advocacy organization, run by and for senior citizens, that has formally existed in the province of Ontario in Canada since 1998. Its key mandate is to advocate for improvements in home care and community services for older residents of the province in relation to equity, quality and accessibility, through monitoring and analysing these services and informing policy makers (see <a href="https://carewatchontario.com">https://carewatchontario.com</a>). This case provides an example of how occupation-based social transformative efforts can evolve in response to a community-based organization's identified need. Care Watch sought to critically reflect on its approaches to social transformation to better meet its advocacy objectives. Through a cyclical participatory process, the group identified key issues related to ageism and use of social media and implemented a series of actions for various levels of transformation. Overall, this case is primarily focused on the transformation that occurred in the organization and its members, rather than the outcomes of its on-going advocacy efforts.

Material for this case was derived through an interview with Dr. Barry Trentham, an occupational therapist and academic involved in the PAR project, as well as publications regarding the project (Trentham & Neysmith, 2018; Trentham, Sokoloff, Tsang & Neysmith, 2015). Quotes from Barry are presented in italics throughout the text, while quotes from articles are cited.

#### **Formation of the Participatory Action Research Project**

The idea of doing a participatory action research project with members of Care Watch started in discussions on the organization's board, upon which Barry was a volunteer member. Based on his knowledge of the organization, Barry knew that being a member of the board provided an opportunity to learn about how senior citizens enact advocacy. As the idea for a research project surfaced through discussions within the board, Barry approached Dr. Sheila Neysmith another academic who was also a board member. In turn, Barry and Sheila worked



together to explore the possibility of doing a research project that would support the organization in their advocacy efforts.

Once the idea was further discussed by the Board, the project was taken up by the Social Action group, a subcommittee of the board on which Barry was also a member. The group of co-researchers consisted of Barry, Sheila, and the Social Action group that was composed of six senior citizens. The first collaborative action of the group involved seeking research funding which was obtained, after submission of two proposals, from a federal Canadian funding agency, the Social Sciences and Humanities Research Council. The group worked together over the duration of the two-year funding period, with the exception of one original member who passed away during the process and was a replaced by a new member. Ethics approval was granted from the University of Toronto's ethics review board.

Underlying this PAR process was a commitment to draw upon and value the knowledge and experiences of members of the advocacy group. Barry emphasized that this commitment was essential as

"This is a group of mostly women – a group of very strong women" and "this group was serious about their work. They were very experienced, intelligent, and influential women aware of their own power".

# **Process of the PAR Project**

PAR involves a cyclical process of reflection and knowledge generation, inclusive of defining issues and gathering knowledge to understand them more deeply; planning, with respect to how to address an identified issue(s); action, to address identified issue(s); and reflection on action, often moving to further clarification and identification of issues. As such, while the overall objective of this project was to inform how Care Watch enacted their advocacy work, the specific aims and actions evolved as the group worked together.

The aims of the PAR project evolved out of a process of dialogue amongst the members of the PAR team. This group identified frustration in their on-going efforts to influence policy makers and engaged in the PAR project as means to strengthen their voice. Overall, the members were

"frustrated with what they felt was tokenism, and they came to frame that as ageism, and then they started telling stories about, 'yeah, when I did this, this happened.' So, there was a lot of pulling apart what that meant."

As the group discussed issues related to its advocacy efforts, questions about why seniors' issues were not a provincial government priority were explored,

"Why is that homecare – that senior citizens chronic care needs – are so bottom-of-the-pile, despite the evidence? There's something else going on here. It's not just about evidence."



Through dialogue, one key issue identified was ageism, such that

"the objectives were really around understanding ageism and what role it plays in our ability to be senior citizens".

Foci of understanding and action related to this issue included deepening understanding of ageism and its impact on the group's advocacy efforts, processes and outcomes, which involved

"a lot of talking about it. We turned it into...what we would call 'exercising citizenship in an ageist society', and there was somewhat of a shared experience that we all do live in an ageist society – that's not a question. Although, what this meant to various members, was very different, and that was very interesting, the process of surfacing what that meant".

Following the PAR cycle, and further detailed in examples below, the group generated, enacted and reflected on strategies to address ageism within their context.

Another key issue identified out of discussions of

"where do we advocate, what are the venues open to us as senior citizens? What gets in the way, what blocks us? What technologies and tools do we use?"

was that of social media and its potential use in their advocacy efforts. In turn, the group engaged in a literature review to understand what was known "about the use of social media by senior citizens for the purposes of social advocacy" (Trentham et al., 2015, p.558). The knowledge generated through this review provided information regarding age-friendly design issues and resources, like the need for training supports, that help to facilitate the use of social media. In addition, the review revealed the extent to which the perceived use of social media by senior citizens is pretty much limited to its use as a source for health care information, reinforcing the dominant image of senior citizens as consumers of health care services. Little literature linked senior citizens with the active use of social media for advocacy. As further detailed with examples below, the group enacted and reflected on strategies to enhance capacity to use social media in their advocacy efforts.

Overall, the PAR process was primarily one of dialogue amongst group members to identify issues, enhance understanding of these, and generate action strategies. It was intended to provide an opportunity for the Social Action group to critically reflect on what they were doing, how they were doing it, why they were doing it, and what some of the root causes were of the things they were trying to change. The Social Action group made it clear they were open to the idea of engaging in a research project, as long as it did not get in the way of their on-going and planned actions. Thus, the PAR process was modified over time to ensure it did not impede



the other activities of the Social Action Group. For example, the time allocated for reflection and when it occurred changed over time:

"Originally we wanted to have twenty minutes at the end of every meeting to reflect. So, what did we do today, what did we think, what questions were raised, based on an interview guide that we'd all agreed upon." However, "It turned out that twenty minutes got side-lined. It wasn't always working, so then we decided, well, you know, this is really important, let's have dedicated sessions just for reflection...They agreed to this which led to some really fascinating conversations. People would get so into the discussion, it was energising."

One of Barry's key roles within the PAR process was to facilitate reflection sessions. A research assistant assisted with the recording, organization and analysis of the reflection sessions, as well as documenting what the group was doing. Barry's role further involved summarizing the documentation and presenting it

"back to the group as a set of proposed themes", and "sometimes they would add to it, and sometimes – often – it would generate a whole other discussion and take things further".

As a board member, a non-senior, and an occupational therapist, Barry was somewhat of an "outsider" to the Social Action group that was composed of seniors, most of whom were women. In this 'outsider' position, Barry's role became to prod and enable organizational change at Care Watch:

"That was my role, to prompt reflection, to prod. But with the organizational stuff, I don't know if it was a destablizer, it was like, what about – like, if we say we've got to do this, don't we need to..."

#### **Actions and Transformations**

Actions taken by the PAR group related to ageism and senior citizenship. A key action was that of group dialogue that, in turn, linked to personal transformation, and spurred actions aimed at organizational and social transformation.

With respect to ageism, dialogue lead to transformations amongst members in terms of their understandings of and awareness of ageism and its impacts on their exercise of citizenship as advocates,

"And I remember one of the men saying that this [understanding the influence of ageism] is what we need to be talking about. This is...it was like consciousness-raising".

Group members reflected on individual actions in their daily lives in relation to age and ageism, as well as on the collective actions taken by the Social Action group



and the Care Watch organization. For example, they discussed larger social images that shape and perpetuate ageism and their relation to these,

"How are images that I say I don't like, they're being perpetuated, but how am I part of that, and am I part of that?"

Through this consciousness-raising process, there was a collective realization that ageism was a root problem, shaping both homecare and responses to their advocacy efforts, that needed to be addressed,

"And if we really are worried about homecare, then we have to address the root problem."

Personal changes in attitudes and awareness, in turn, spurred organizational change; that is, the Social Action group "were taking actions that they had traditionally done, with a bit of a spin." Barry described how the dialogue about ageism influenced the strategies used for advocacy. For example, during letter writing campaigns related to provincial and federal elections, awareness of ageism influenced how letters were written, how partnerships were formed with politicians, and how they came to reflect on how they were being treated, responded to and interacted with:

"we were doing two things: what are we doing, and where do we see ageism happening? So while they're talking about advocacy for homecare, we're picking up on when that guy said such and such, what did that mean?"

At the level of social transformation, the group engaged in actions aimed at broadening awareness of ageism and enhancing dialogue regarding its constraining effects on senior citizens' lives and homecare reform. For example, the Social Action group presented on ageism to the broader Care Watch membership:

"So we were collectively making sense of things when it was coming to unpacking ageism and resisting ageism, so this new learning turned into [Annual General Meeting] presentations".

These presentations also effected change by reaching people who were members of other senior citizens organizations:

"And there were other – there were senior citizens from other senior citizen groups...they're all interconnected. So, they then built on how people were talking about ageism, what they experienced, what it was."

Issues related to ageism also were addressed in presentations that members of the Social Action Group gave within political forums and conferences. One way the impact of such presentations was experienced involved seeing how audience members subsequently changed their language use:



"I think of language and how it's used, but the fact that a senior citizen gave a keynote presentation in the morning and challenged people's language, asking the audience, 'when did we take the citizen out of senior citizen? 'And in the afternoon, ministers, physicians and others were correcting themselves and saying senior citizen. Whether that sticks or not is not so much the issue, but what is important is that they're thinking about their language use."

The group also produced a series of "one-pager position papers" addressing various topics, including ageism, as a means to

"raise awareness, and promote a dialogue." These "one-page factsheets were distributed everywhere we could distribute them – every place we went. And actually they were kind of popular, people gravitated to them."

As well, the group, combining their concerns with ageism and their aim to expand their use of social media, also started a blog,

"It was another way to make sense of the issues through this blog on ageism."

Aligned with the PAR process, reflection on action spurred identification and dialogue regarding additional issues in order to inform further action. For example, in writing the one-pager that addressed issues of language used to refer to themselves and those with whom and for whom they were advocating, the group enhanced their awareness of the importance of labelling:

"What do we call ourselves? We looked at the literature and I think that was one of our fiercest debates – are we elders, elderly, seniors?"

# Through this dialogue

"the notion of reclaiming the language issues that every other marginalized group has sorted through, this group was sorting through. And that was exciting because...we realized that in the end what we call ourselves isn't the only issue; it's how we talk about it and being conscious of the images or messages our chosen labels reflect."

Through writing the various one-pagers and engaging in dialogue, further organizational change was spurred as the group eventually came to frame issues faced by senior citizens in relation to rights,

"That came at the end, what does it mean to be an older old person? And yes, we're challenging myths and stereotypes and we talked about the responsibilities of citizens to contribute, but at some point our citizenship becomes about rights and...like, I don't need to contribute to the community any longer. I have the right to be looked after."



In relation to social media, within a context in which there was an increasing use of on-line technologies by advocacy groups, a group member indicated that this can be experienced as a form of social exclusion given "that while younger people grew up with this technology, many older adults are left 'in a void' and at a disadvantage" (Trentham et al., 2015, p.558,555). The group discussed if and how they might add to their long-standing methods of getting their message out to policy makers and other stakeholders by using social media:

"One big piece...was the use of social media. Because we got into the letter writing, that was the way things were done: you have a political forum, you write lots of letters and that's how it has been done for years."

The group discussed members' cynicism and suspicions regarding social media as a tool for advocacy, and came to a reluctant acceptance that was something the group needed to explore,

"And we started looking at social media...there was a lot of cynicism around Facebook and Twitter...but the world was changing and we acknowledged that. Reluctantly there was some acknowledgement of that, like, we just can't write letters anymore".

Given this reality, an action objective of the PAR group became to "investigate and better understand how to use online media for senior advocacy purposes" (Trentham et al., 2015, p.559).

To address the issue of social media use for advocacy purposes, the group both engaged in a review of existing literature and educational activities. The PAR group members learned about social media together, with support provided by occupational therapy students that Barry was able to connect to the group as a resource:

"We actually did two things: we thought, okay, we don't really know much about this Twitter stuff and Facebook, but we know we have to play the game, so let's learn how to use it. So, we had workshops actually here in the OT Department. Students – OT students would work with the older advocates, they would talk a little about what they did, and the OT students would help them set up a Twitter account, Facebook account."

Reflecting on the workshops, the group identified that not everyone took up the social media learned, due to various barriers. This led to identifying the need for another layer of organizational change:

"We quickly discovered it doesn't matter how well you know Twitter and Facebook, you need human resources to make them happen. So, we pushed for this. As we had some money and were about to hire a staff person, we requested for that person to have social media skills – she or he had to be social media savvy. So again, that shifted the organizational structure in a way, in a sense, as to what skills and resources are needed and valuable."



In addition, organizational capacity to take up technologies was enhanced via creating resources, such as a Dropbox and a library of PowerPoint slides addressing ageism. Although wholescale adoption of social media was not realized, changes did occur:

"Even though all group members are not using Twitter or Facebook like I was hoping they would partly because of staffing. Eventually, the organization had to reduce their budget and no longer had staff resources dedicated to social media. Their website is better than ever though, and they're using it in a way to engage. I use it to inform my teaching...So it continues to foster change."

# **Occupation and Processes of Transformation**

As an occupational therapist and scientist, Barry, in reflecting and writing about the PAR project, situates his involvement and action in relation to occupation and a critical occupational perspective, although this was not an explicit topic of discussion or guiding framework during the project (Trentham & Neysmith, 2015). At a broad level, the project can be viewed from an occupational lens as a process that aimed to enable the occupation of advocacy and the enactment of senior citizenship. Barry frames citizenship as an occupational role. The PAR process enabled deeper understanding of this role, based on the experiences of this group of senior citizens, of how their occupational possibilities for citizenship are "constrained by conventional ageist views on ageing as reinforced and informed by successful aging concepts situated within a neo-liberal political context" (Trentham & Neysmith, 2015, p.174). As such, a critical occupational lens provides a means to understand citizenship as a type of occupation that is situated within socio-political conditions and that is differentially possible for citizens based on age.

The PAR project offered insights on how "ageism, as a social force, is experienced and resisted through the advocacy work of a group of seniors citizens" (Trentham & Neysmith, p.175). Through actions in the PAR project, members resisted the exclusionary power of ageism and challenged the limited array of occupations associated with older people, particularly in health care contexts that often focus on self-care or activities of daily living. As well, group members engaged in occupations, such as social media use, writing together, or delivering presentations, throughout the PAR process. These various forms of individual and collective occupational engagement changed their organizational and larger social environments, through the presentations and materials that disseminated information about ageism, in ways that supported their advocacy occupations.



#### Wrapping up and 'spin offs'

The formal PAR project ended when the research funding was completed. The time-limited nature of the project fit the needs of the Social Action group, providing a process for reflecting on what they were doing, how they were understanding the issues they were trying to change, and for planning how their changing understandings would inform how they enacted citizenship and advocacy as they continued with the work of Care Watch. In speaking of the funding coming to an end, Barry emphasized that there was a sense that

"new things are going to be happening now. We've got a new board coming in...a changing of the guard, so it was a natural kind of ending for the project."

At the same time, the impacts of personal, organizational and social changes that arise out of PAR projects are difficult to capture, as they may be neither linear nor quantifiable. Rather, as experienced in this project, on-going ripple effects may occur through "little connections", in "little bits and pieces", and in intersections with other initiatives. For example, "near the end of the project there was this initiative to create an anti-ageist network" which partly stemmed from others in the community becoming aware of the actions taken to address ageism by the members of the Social Action Group:

"The group brought in a few more people interested in this issue...they'd heard about what we were doing, so this network came together and actually there was initially quite a large group of people."

While the network itself did not build as anticipated, other actions happened that were

"built on some of the issues that we examined through the SSHRC [research funding source] project."

For example, a few members are now part of an improv group of people over 55 who decided to play "with issues of age and ageism". As well,

"a few people carried on and developed a number of vignettes based on the group's work. They gave a series of interactive theatre performances, one at Toronto Public Library, which brought in a lot of people, and engaged them in discussions on the experiences of ageism and how it plays out".

This PAR project also contributed to the formation of a partnership with the City of Toronto to do a "We're Still Acting Out" project, successfully obtaining funding to develop and pilot test a module and videos on ageism. These resources were distributed to several hundred local community organizations (Trentham & Neysmith, 2015). (For additional information on anti-ageism resources, see <a href="https://carewatchontario.com/knowledgebase/research-reports/ageism/">https://carewatchontario.com/knowledgebase/research-reports/ageism/</a>).



In summing up what the PAR project achieved, Barry proposed it was about deepening both the group's and the broader societal understanding of ageism, enhancing the capacity to name it, bring it to awareness and promote dialogue on how to address it:

"It initiated a conversation. It deepened a conversation around ageism... Much of what we read in various seniors' care policy reports refer to ageism, but it more typically comes down to the individual level, how nice you are to old people...This project took the conversation to another level. It took that conversation further, and asked things like, how are our policies reflecting ageism?"

#### **Best tip:**

"Expect ambiguity, expect some fuzziness along the way, changes in direction; remember the importance of establishing a relationship earlier on; and make sure your agenda aligns with the agenda or the identified needs of the group that you're working with."



# Langa Cheshire Home – Community Development Practice Site, South Africa

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#### **Introduction**

Langa Cheshire Home is a Community Development Practice (CDP) site that has been since September 2017 for final year occupational therapy students at the University of Cape Town.

Langa Cheshire Home was opened in 1990 and is one of 18 independent homes in the Cheshire Homes franchise in South Africa. Cheshire homes is a non-government organisation that offers assisted living for persons with disabilities. The staff members at the home include a manager, secretary, driver, laundry lady, cleaning staff, cooking staff and carers. The Langa Cheshire Home is situated in Langa, Cape Town's oldest township (www.sahistory.org.za/place/langa-township). The majority of the people living in Langa are black, isiXhosa speaking citizens (census2011.adrianfrith.com/place/199028), and this is reflected in the demographic profile of persons with disabilities (PWD's) living in the home. Langa is a predominantly a low socio-economic area with limited resources to support persons with disability (PWD) in Langa and as a consequence the home also serves as a venue for various meetings for PWD who reside in the Langa community.

There are 25 residents with varying diagnoses and severity of impairment living at Langa Cheshire home. Their diagnoses include: spinal cord injury (quadriplegic and paraplegic), cerebral palsy, traumatic brain injury, cerebrovascular accident and intellectual disability. Almost all of the residents are dependent on carers employed by Cheshire home to assist in their activities of daily living. There are often some residents who are recovering from pressure sores and spend most of their time in bed. The carers rotate between day and night shifts, with 1 head carer and 2 carers on duty during the day and 3 at night. The occupational profile of about half of the residents in the Cheshire Home includes sedentary and social occupations within the home, such as sitting around in small groups, talking to one another and smoking. The remaining half of the residents at Cheshire Home leave the property during the day to participate in different kind of education; attend various meetings; socialise in the neighbourhood or to go on privately arranged errands or outings. These PWDs frequently travel to their various destinations in their wheelchairs, sometimes for far distances. Doing this can be precarious for PWDs in Langa since there are no pavements at many sections of their journey or where there are pavements, there are no ramps between the



pavements and the road. This leaves the PWDs with little choice but to travel in their wheelchairs on the open road. When drivers abuse alcohol and drive recklessly, as sometimes occurs, PWD using the roads with their wheelchairs face the danger. The high unemployment rate in South Africa (27% https://tradingeconomics.com/south-africa/unemployment-rate) is reflected in the scarcity of paid work or employment for people living in Langa and especially so for PWDs in Langa. While some PWDs in Langa often access opportunities to participate in learnerships, this very rarely translates into meaningful job opportunities.

# **Purpose and objectives of this Cheshire home**

Langa Cheshire Home is a residential facility for persons with disabilities. They provide housing for persons with disabilities who, for various reasons, cannot live by themselves or with families in the community. Langa Cheshire Home receives a South African government funding subsidy through the Department of Social Development and is also in the process of attaining funding from the Department of Health. This subsidy from the state only covers 30% of the operating expenses of the facility. These costs include water, rates, electricity, staff salaries, self-care consumables, food and transport for residents of Langa Cheshire Home. The Langa Cheshire Home management is expected to raise additional income through fundraising initiatives. Their fundraising activities include charitable appeals for donations; applying for funding to corporates or the National Lottery; selling second-hand items and collecting cash donations from the public by standing with tins in shopping malls.

Residents are provided with three meals a day, ad hoc social work services and transport only to clinic and hospital appointments at local health facilities. Residents access minimal rehabilitation services at these health facilities since these rehabilitation services are mainly offered at secondary and tertiary hospitals. Most of the residents with disabilities would thus have received rehabilitation services as part of an acute service. The primary focus of their follow up clinic or hospital appointments is to monitor and check up on medical needs.

Langa Cheshire Home endeavours to be a temporary residential facility in that residents are expected to return home with the necessary support systems in place. This however is not always possible in the context of South Africa where persons with disabilities still continue to be confronted with stigma and discrimination that is evident in the inaccessible environment, lack for opportunities for work or participation, limited access to housing and unemployment. The socio-economic challenges of unemployment and access to housing also affects the majority of non-disabled people in South Africa. Given the multiple challenges, the Langa Cheshire Home residents often remain living there



indefinitely and thus there is hardly ever space for new people to access this residence.

# Change from traditional clinical practice towards occupation based community development.

The site is told up front what to expect from students. The students are expected to deliver occupational therapy services and there are also Community Development Practice skills that students need to develop.

When students begin working at the Langa Cheshire Home, they start conducting a context related assessment (Galvaan 2017). A fundamental aspect of this assessment is building a relationship with the various stakeholders at the organisation and learning more about what the needs, opportunities and challenges to occupational engagement are within the context. The findings are co-produced and are communicated to the organisation, with the organisation often valuing the perspectives of others on the organisation. It has turned out in the past that the context related assessment findings have benefited organisations in that they use the findings in their reports/funding proposals. The participatory nature of the context related assessment allows the people with whom the students work to influence the direction of this assessment process and to reach consensus on the focus of the intervention/strategy. During this assessment, the students explore and analyse the emerging patterns of occupational engagement, obstacles to occupational engagement and potential opportunities for participation for PWD.

"For instance, there is an open piece of land in the garden which could potentially be turned into a vegetable garden as lots of residents mentioned that they used to enjoy gardening and it also has the potential to yield income and supplement food budget for the home.

Or another example: The kitchen is equipped with industrial appliances and the female residents expressed repeatedly that they miss cooking. The cook and the residents have good relationships, and this could be a potential collective or individual occupation in which residents can participate as both means (meaningful and purposeful) but also selling food to the local community. This could aid in growing the local economy and could also yield income for individuals or could supplement Langa Cheshire Home's budget deficits.

Or another example: The residents have expressed that they wish they could learn to use computers. The dining hall is very large and has the potential to house at least 10 PCs and workstations. This could serve as an opportunity for the organisation to gain an income in providing basic computer training to both disabled and non-disabled persons in Langa. The manager has a good relationship with an IT company who previously donated a TV and a laptop. There is potential



for this relationship to be explored and residents have also identified a trainer who they met at the library.

The above examples still hold as potential occupations but have not materialised due to the current incapacitation of the home, relationships and politics. But the possibility is there, and students continue to work towards it."

This is informed by the reasoning questions associated with the Initiation phase Based Community Development of Occupation (https://vula.uct.ac.za/access/content/group/9c29ba04-b1ee-49b9-8c85-9a468b556ce2/OBCDF/index.html). There are three broad questions that the students use. The first question is trying to get an understanding of an occupational profile of the community, so what occupations are people engaging in and what occupations are people not engaging in, and then to unpack that further. The second question is what the gaps in participation are that the specific group or community is experiencing. So, what are the things that are preventing people from engaging in occupations or stopping participation. And the last question is the students and the community together to think about what potential is there for more engagement. So, the students use those questions as broad questions and then use them to guide the conversation with the PWD's and actually to explore those questions in whatever way it comes up. In addition, students implemented a developmental reading (Westoby & Kaplan, 2013) of Langa Cheshire Home so as to gain an understanding of the organisational context in relation to the organisation's capacity to support the PWD and promote occupational justice for and with residents. The key findings revealed that the main factor hindering the residents' wellbeing was the various poor and broken relationships between the various staff members and with the residents and the staff members and residence management and with the Langa Cheshire Home governing board. Another key factor was that the residents were excluded from decisions that affected them, including decisions about the operations (like meal preparation, medication management) of the home. The Residents' Committee (RC) of the home had been disbanded by the manager.

While the students uncovered these insights into the organisation, the Cheshire Home management was eager for the occupational therapy students to offer therapeutic and rehabilitation services to the residents. During the first weeks of the placement at the Cheshire home, the students and clinical educator were immediately expected to go to the individual resident's rooms to assist residents with activities of daily living or to offer individual therapeutic input. This was tough to navigate as the students and clinical educator recognised that there were contextual needs in addition to the individual needs. The compromise was to explore what rehabilitation services students could offer, with students using most of their initial time to conduct the above context related assessment. The clinical educator and students continued to dialogue about the possibilities for services with the Langa Cheshire Home management and the residents, like to do training



with carers around transfers, positioning, seating, using assistive devices in feeding and ADL, etc. This was fiercely resisted by staff who did not attend any of the training due to unresolved human resource grievances regarding their pay with management. The tension between the desire and need for traditional clinical practice and community development practice remained a challenge to be navigated. In the end it was agreed that the students would possibly do training in the future with carers regarding safe transfers, bed mobility, positioning etc and a link was made between Langa Cheshire Home and a student-run clinic service, namely SHAWCO. The outcome was that SHAWCO agreed to hold a clinic on one Saturday per month at Langa Cheshire Home. This clinic includes voluntary services offered by occupational therapy students practicing in the domain of physical rehabilitation.

# Social transformation facilitated by the students.

Students focused on building authentic relationships (Taylor, Marais, & Kaplan, 2005) with and between residents, staff members and members of the management team. Initially everyone resisted or was suspicious of the students. The students made explicit their desire to get to know each person better and actioned this by hosting multiple dialogue spaces. Here various techniques and methods were used, where dialogue is central. Problem-posing, for example, helps to mobilise a group to move into action as collective and dialogue spaces are needed so that these actions can be considered and decided on as a collective. This was however perceived by residents and staff as "just sitting in a circle" and "wasting time just talking talking talking all the time". It was hard for the residents, staff and management to see how these efforts contributed to building a shared understanding on the possibility of revitalising the Residents' Committee. This committee was seen as a strategy to representing the residents in decisions which could influence the outcomes for the residents, staff and the organisation. However, another urgent and pressing issue was that the city was experiencing water restrictions, the threat of "Day Zero" and had a R33 000 water bill. The two issues thus converged and the students engaged the various stakeholders in dialogues as a collective to discuss and reflect on the pressing issue of (and occupations related to) saving water. The students focussed on water saving plans for the home where residents, staff, carer and the management members were all required to give their input into a plan that could be implemented.

While the residents, staff and management where developing a plan to save water in the home as a collective; the dysfunction in their relationships was revealed. And it provided a great example on which to critically reflect together regarding relationships in the home and how it affects being a resident, a staff member and management. Through applying action learning, the group members began to recognise the effect of their relationships on many matters that affected them as a collective. Although the home did not have a television, we drew on resources



and organised movie afternoons to draw carers and staff together into one space after lunch. Whilst watching local comedies the members, carers and some staff had experiences of 'doing' together. The manager even joined in one afternoon after hearing the squeals of laughter. The developing of the 'we' in the sentences above was central to our work.

Continuing to build the Residents' Committee's (RC) capacity was the focus for several student placements using various techniques (like problem posing, action learning, vision building, addressing elements of incapacitation through some skills training, mapping) that focussed on strengthening partnerships, working collaboratively, facilitating meaningful dialogue and action learning. One of the outcomes of this process was that each of the RC members chose portfolios to fulfil which they felt passionate about. This included Chair, Secretary, Treasurer, Management Liaison, Project coordinator.

Students adopted a supportive role which focussed on facilitating critical dialogue spaces in which the RC could critically reflect and learn from their actions. The students' role became that of supporting the RC to develop cohesiveness so that they could represent the residents and carry out their decided mandate. An important aspect of this was working with the RC Chairperson.

The students worked collaboratively with the chair of the RC and positive shifts in how he enacted his agency was noticed over this time. During that 1st block in 2017, he was hardly ever seen as he was always in bed due to continuous pressure sores. His involvement in the campaigns was limited to that of an ad hoc participant in dialogues and he had no involvement in the Home. Appreciating the value of the dialogues, he expressed more interest in collaborating with the students to work towards changes in Langa Cheshire Home. Over time he gained confidence in voicing his opinion and expressing his ideas and many of the residents began to show respect for his reasoning and contributions. This resulted in him being elected as chairperson of the RC. He committed to remaining intentional about maintaining a healthy and strategic relationship between the residents as a collective with management. As a Chairperson he has been able to hold meetings with residents and management; attend board meetings and represent the residents, putting forward agenda points and solutions in a way that respects everyone and contributes to managing the dynamics of the home amicably. While we do not take credit, we recognise that he has now also purchased a vehicle (through sponsorship from the Chris burger foundation) and enjoys a healthy social life with many visitors visiting him at Langa Cheshire Home.

#### Results

For the clinical educator, the work above was seen in relation to the importance of supporting Langa Cheshire Home to become a capacitated organisation, providing good quality care to residents, who are active in the organisational



structure and able to experience wellbeing through their participation in occupations. The capacity here refers not just to the capacity for the home to meet operational cost requirements, but for the home to be a place that nurtures residents' opportunities to participate and creating an environment that allows for residents to make occupational choices that reflect their agency. The clinical educator had to do all this authentically, model transparency but also uphold confidentiality about sensitive matters. She also had to bear in mind the seriousness of pressure sores, malpractice and neglect within group homes, ethical practice and working developmentally to influence sustainable solutions designed and actioned by residents and staff from the inside out. The seriousness of neglect had been foregrounded in the recent Life Esidemini tragedy deaths 143 that involved the of people at psychiatric the Gauteng province of South Africa from causes including starvation and neglect and thus working with Langa Cheshire Home to build their capacity was of critical importance. There is still much to be addressed. "It will come" is something the clinical educator has always told her students; this is the possibility that they see together.

"The social transformation part lies in building the capacity of the organisation and the way in which this is done. This is a goal that is very, very long term. The same long-term aim is kept for every block but the main aims change. The potential opportunities for participation and engagement as mentioned above are still on the cards once the organisation actually has the capacity to initiate and access these opportunities. Social transformation is not only outcomes based but is also reflected in a community's ability to bring about change from the inside out and no longer to be dependent on outsiders to solve. "

After two years, the following outcomes change has manifested:

- The RC has regular 'House Meetings' where ALL the residents are called to meet in the dining room to discuss their grievances and convey these to the RC to take forward with management.
- The RC has a seat on the Langa Cheshire Home management Board and has attended at least one Board meeting.
- The RC was able to successfully have a conversation with management regarding access onto and out of the premises, enabling family members to visit and freedom to socialise off the premises, especially over the weekends, etc.
- The residents have 'tested out' the RC in terms of the grievance process and have placed their trust in them to represent their voice. The RC too, has proudly risen up to this role.
- Residents are more involved in the planning and actions of various fundraising events.



- Practically, the home now has a working TV in the dining room with a DVD player from where residents can watch TV or a series or watch a movie together when they wish.
- The residents attend SHAWCO clinics where they access therapeutic services and are referred to local health services and therapists to attend to physical health needs where indicated. The Langa Cheshire Home's management is starting to value the voices of residents (although there is still room for improvement). Carers are starting to warm up to students and we suspect that training (as a gift) will soon be on the cards.

# Occupations incorporated in the development

Residents are now able to watch TV, residents and staff are both able to engage in fund raising opportunities for the Home, some residents now have freedom to move into and out of the premises to socialise, go to the library, and other less mobile residents have been seen playing dominoes. These occupations are commonly performed occupations in the Langa community that were not participated in previously by the residents while at Langa Cheshire Home. While these are not necessarily occupations that have completely transformed society, it is important to notice that for this site this is a shift from the site being like an institution to a place of belonging. So, the occupational risk factor of occupational deprivation is being addressed. Participation and engagement in healthier occupations will follow. There were and still are many opportunities for further engagement, but the incapacity of the Home is presented as a more global obstacle for participation. Occupations could not be forced onto residents or staff otherwise trust would break, engagement would not work developmentally and it would reinforce the notion that outsiders are the initiators and sustainers of doing. The results of such an approach is known, where communities engage and participate when students are around and then stop participating as soon as the occupational therapy students leave and wait for the students to return.

# Sustainability and continuity

The plan is to continue working with what emerges and for the RC to continue being supported as they develop their own capacity to be more agentic in their participation.

As far as applying for funding is concerned, the NGO sector in South Africa is very saturated in terms of funding opportunities. Crowd funding is gaining momentum in the NGO sector but this requires internet connection and access to laptops. The management lacks skills in fund raising, marketing, etc and this also adds further to the financial burden. Another obstacle that NGOs face is the donors themselves and their criteria for funding and monitoring and evaluation. Most donors want



results but do not invest long term for real change. They fund short term solutions and not this 'invisible' long term work that only yields results over time. So, donors will inject funds, rather than invest in long term processes for the organisation and community. The NGO sector is large and employs many people, making the tension between satisfying donors to get funding for salaries and projects vs working developmentally with communities very complex. There are many courses one can go on to acquire these skills. These courses cost money and not all organisations have the means nor see the value in investing in their managers to attend. There are brilliant funding models and social enterprise initiatives that other NGO are thriving on- mostly international connections, large consistent bequests and mostly dependent on access to circles of wealth and privilege. The NGO sector is not immune to the systemic effects of the Apartheid system in many respects.

With regards to the residents, it is envisaged that the actions taken by the RC may grow towards income generation. The ideas for selling food to the community is but one of the possibilities for the residents to pursue. As the RC strengthens and the collective becomes more active, support and the conditions for income generation may also be more fertile. They should be looking into innovative ways to source, broaden their networks and access Corporate Social Investment opportunities. These are all highly dependent on skills of the manager to do this and circles of influence.

Community Development Practice (CDP) occupational therapy is new for this site and they are learning about it as they watch the students' practice. When negotiations and planning around site development started, the difference between clinical and community development approaches to occupational therapy is explained extensively in both verbal and written format; but because this work lies in the intangible/invisible realm, it is challenging to demonstrate explicitly how a process is being facilitated. This can be improved by communicating shifts in the process on a more regular basis, so that shifts can be pointed out as it occurs." For example, the change in attitude of the residents towards management must be explicitly linked to the numerous and sensitive dialogue spaces facilitated by students. Another example: Residents and staff watching soaps together on TV in the afternoon needs to be explicitly linked to the (now) capacitated voice of the RC who facilitated their own meetings with management to get the TV repaired and installed on behalf of the residents." These links between the invisible work and the tangible outcomes needs to be made more clear so that the 'work' of CDP is more clear.

The residents and management agreed to share their story and invite you to make contact with Mr Mbadlisa (the manager) if you are interested in supporting their organisation- please contact the authors for these details.



# Tip for a colleague, who wants to start this work

Get to know your own community, because it is very easy to open the hospital folder and to only work with that information.

As a tip prioritize home visits, getting out of the building more, and engage with your patients/ clients. Partnering with your patients in trying to understand where they come from and not just measuring motion, strength, tone etc... Do real interviews and broaden what you want to find out. Things just unfold from there, because you find that, one week you will get a patient from community A, and in two weeks you get another patient from community A, and when you go out to community A you can connect and start building a network in the community. So, really just start thinking little bit beyond the individual.

A first step would also be to talk to and to learn from people who are already doing the work and create networks, rather than start doing it on your own.

Do not underestimate the value of critical reflective spaces and how it helps people to critical reflect on what they do and those invisible factors that prevents them from doing or shape how things are done, that directly affects their health. Engaging in critical dialogue enables people to shape each other's perspectives and enjoy the benefits of collective thinking, reasoning and learning in their development.

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# Internationale StadtteilGärten Hannover e.V. (International City District Gardens Hanover), Germany

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#### **Overview**

International City District Gardens Hanover (*Internationale StadtteilGärten Hannover e.V.*) is an association founded in spring 2007, which currently looks after six community gardens in the city of Hanover, Lower Saxony, Germany. The first garden was created in 2006 in a socially disadvantaged district with a high proportion of immigrants. From the very beginning, the idea of urban gardening was combined with the approach of a cross-cultural partnership in order to support the social inclusion and empowerment of people with a low socio-economic status and migrant background. The association is committed to the use and utilization of (semi)public spaces and food production for basic self-sufficiency in socially disadvantaged districts. The gardens are sites of food production intended to function as meeting places.

### **Development of the initiative**

International City District Gardens Hanover was initiated in 2006 in the Sahlkamp district of the city. Several hundred families from 60 different nations live there. Next to unemployment, youth violence and drug abuse are the major problems in this neighbourhood, which is characterized by high-rise buildings.

Without any job prospects or a secure residence status, at the brink of subsistence, the adults often keep retreating further and further, hardly participating in social life and referring only to their own ethnic networks. They have no opportunity of exchange with German people, so that they do not apply the language skills they have already acquired. Spatially, the district is characterized by an accumulation of high-rise buildings whose inner courtyards on the underground car park roofs were heavily garbage-strewn or polluted by rubbish. These dead areas could not be used, did not represent a suitable place for children and were perceived by the residents as threatening and unsafe.

An employee of the city of Hanover wondered how an urban gardening project could be initiated in Sahlkamp. On the one hand, he was inspired by the International Gardens (*Internationale Gärten e.V.*) in Göttingen, a city 120 km



away in the same federal state of Lower Saxony, which had been founded in 1998 as the first intercultural garden project in Germany. There, the positive effect of community gardening on the coexistence of people from different cultural backgrounds was recognized early on. A second source of inspiration was a lecture on urban agriculture in Cuba, where the idea of self-sufficiency is in the foreground. When the city employee brought the idea of an intercultural community garden to the district as a contribution to self-sufficiency in food, this appealed to a great many people, especially from residents in the immediate area. At the same time, a residents' initiative was founded to promote a more responsible use of the green spaces in the district (especially the garage roof plateaus). But allies were also found from other initiatives and institutions, such as the police or the church, since this was the first intercultural garden initiative in the city of Hanover and it was recognized as an exciting project.

From mid-2006, the residents' initiative developed plans for further action together with several municipal employees as well as workers from social institutions. The principle of partnership-based cooperation was taken into account right from the start, i.e. the residents were directly involved from its initiation.

In autumn 2006, a major clean-up operation was carried out for the first garage roof, in which around 60 people participated. The areas were measured and the future horticultural use planned. In April 2007 the garden was officially opened with a planting festival. In order to ensure self-sufficiency in food, the garden area was to be used by 15 families. Since 40-50 families from the district took part in the initiative, however, it became clear early on that more space was required and in summer 2008 the second garage roof in Sahlkamp was converted into a community garden. Additionally, in 2007 the *Teegarten* Hainholz was opened in another city district. This is a park-like neighbourhood garden suitable for concerts and workshops.

Due to the rapid development of several gardens, it was already foreseeable in the founding phase of the association that a greater organisational effort would arise in the longer term. Gardeners from the association who trust themselves to take on this task were hired as office workers or employed as board members on the basis of so-called "one-euro jobs". <sup>2</sup>

The municipal employee responsible for the district cultural work in Sahlkamp was able to take care of the acquisition of project funds within the scope of his work

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<sup>&</sup>lt;sup>2</sup> One-Euro-jobs are activities not covered by social security, which must be in the public interest. They are also called work opportunities. They are provide assistance on the back to employment for recipients of basic unemployment benefits (*Arbeitslosengeld II*). They can only be offered by suitable institutions, e.g. associations or public institutions. The activity must not endanger a job subject to social insurance contributions. The job centre pays a subsidy to the unemployment benefits. Source: https://www.arbeitsagentur.de/lexikon/ein-euro-jobs (accessed on 17.3.2019)



right from the start. Since 2008, specific applications have been made to the city council in order to receive institutional support for the association. This was approved in 2012 (in a reduced form), making Hanover the first municipality in Germany to permanently finance the position of a managing director and coordinator for a gardening association. The managing director, Eberhard Irion, is also honorary coordinator and mouthpiece of the Garden Network Hanover, an association of all urban gardening initiatives, community gardens and social garden projects. In January 2018, a second city-financed office position was filled.

Currently the association has 76 members, 70 of them active gardeners and 6 supporting members.

# Who is involved and how they work together

The original target group are people with a migrant background in a difficult economic situation, for whom gardening is to offer self-sufficiency in food, the establishment of social contacts and the experience of self-efficacy. Since the association maintains different gardens in the city area, the group of gardeners organized in the association has become quite heterogeneous. The *Bienengarten* (Bee Garden), where you can learn beekeeping, also specifically targets people interested in ecological issues. The community garden *Rübenacker* (Turnip Field) in Hainholzen tends to reflect a young and academic environment. In addition to a relatively large variety of users, the community gardens in Linden-Süd also show a tendency towards single mothers with a Turkish background. In different gardens different groups are dominant, depending on the location of the district, but also within the district, e.g. in Sahlkamp women are more active in the Spessart Garden, while men do the work in the Steigerwald Garden.

All offers should be as budget friendly as possible so as not to exclude anyone. The association therefore only charges a relatively low membership fee. The membership fee for financially disadvantaged families is donated by supporting members. Non-members are also invited to take part in garden activities; especially on action days and at celebrations, the participation of people from the district is high.

The community gardens within the association, which are designed for self-sufficiency, consist of individual beds for families, i.e. there are no fully communal bed areas, but responsibilities are formally divided. Within the bed structures, however, there are co-operations between families. The different groups in the association do not keep themselves to themselves, but arrange meetings, getting to know each other and mutual exchanges are considered important. Within each district there is a strong exchange between the gardens; the exchange with other districts is actively supported and organised by the office, e.g. through joint actions or little parties.



Due to the transparency within the association the members know the high workload which is connected with running the office and welcome the fact that two responsible full-time office posts are financed. Thus, no conflicts arise between the full-time and honorary persons engaged in the association. The management plays an intermediary role, particularly in negotiations with the city administration and with property owners, and acts as a fixed point of contact for the contractual partners. If situations of conflict arise within a garden community or between gardeners and residents, the management acts as moderator and mediator. This is an important relief for the gardeners, who are not able to withstand stress very well, e.g. due to flight experiences as refugees and lack of social contacts.

In addition, the management (re)presents the association at events within the city (e.g. at district festivals, network meetings, general assembly of the city senior council), but also in the region. The aim is to raise awareness of urban gardening in the city and to disseminate gardening expertise. On such occasions, the management also actively involves the gardening families, who would be less likely leave their district on their own initiative, so that they can get to know exciting new topics, people, institutions or even new cities.

# **Funding and support**

Since the topic of gardening in general and resource-saving communal food cultivation in particular have a very positive connotation, International City District Gardens Hanover has no problems in acquiring new garden areas. This is in contrast to other urban gardening initiatives in the city, which are strongly affected by the negative effects of the partial privatisation of public space. Instead, the city of Hanover recognizes that it can save costs in the maintenance of areas by setting up an intercultural community garden. However, the properties that the association manages must be available in the long term so that people can actually "take root abroad". Many urban gardening projects are short-term and temporary in nature. The aim of Internationale StadtteilGärten, however, is to provide people with a place where they can really establish trust in their own skills so that they establish a connection with the soil of their new country by literarily "growing roots" - if you grow roots, you cannot be expected to simply pull them out and transplant them to a new place, if the lease on your garden project is suddenly terminated. The association needs contracts with the city of Hanover guaranteeing the long-term use of properties, i.e. garden space.

Due to their strong institutionalisation, the International City District Gardens Hanover are no pure bottom-up initiative. The management is responsible for the good financial position of the association by managing its resources and by raising funds or donations. The work with the volunteers in the association, who are confronted with many problems, requires a great flexibility within the course of a project and regularly contradicts the narrow framework specifications of external



sponsors. Partnerships with donors or clients must also be morally justifiable (e.g. with regard to the pursuit of sustainability, businesses without connections to the arms trade).

There are partners from the public sector, civil society and the private sector, at the city district level (e.g. with the contact officers of the police), in the municipality, in the region and throughout Germany.

Within the city of Hanover, the International City District Gardens maintain a partnership with the Agenda Office, i.e. the Sustainability Office of the city administration, and support it in projects such as the application for the nationwide sustainability prize. The association acts as a consultant for the Department of Environment and Urban Greenery and the City Green Spaces Department when it comes to supporting new initiatives in the field of urban gardening. Since the state parliament of Lower Saxony has its seat in Hanover, the association is also the contact for state politicians interested in the topic.

Eberhard Irion emphasizes the importance of practical exchange, as it is expressed by the international network idea, which is represented by the Transition Town movement, for example. This requires additional voluntary work or free activism outside his work role as a city employee. He is involved in the Hanover Garden Network and in networking activities at the state level (e.g. through a close exchange of advice with the Göttingen International Gardens) and at the federal level (in the network of advisors for the foundation Anstiftung, which carries out research into commons, do-it-yourself and sustainable regionalisation and supports activities in open spaces such as community gardens or intercultural gardens). He could not achieve this commitment in the Germany-wide network of community gardens with his communally supported position.

"For me it is very important that we not only have this network idea on a theoretical level, but that we also try to get a practical effect out of these many networks in which we are. For example, that we provide each other with consulting services or that perhaps at some point we will be able to loan financial resources to each other based on a principle of solidarity, or that we can exchange material in order to spare our scarce financial resources".

## Sustainability and planning

The association receives sustainable financial support from the city because it achieves a certain positive effect for the entire neighbourhood, and this is an advantage for the acquisition of external funding.

The successes of the garden initiative are seen in the fact that it brings together people who would otherwise not meet in everyday life for various reasons. The district gardens are helping to establish peace in the neighbourhood; the rate of



vandalism around the gardens has fallen sharply. This is also reflected in the increased demand for ground-floor apartments, which were previously difficult to let due to fear of burglary.

In the partnerships it enters into, the management is mindful of sustainability, i.e. that the invested expenditure reverberates positively, e.g. in the form of political or financial support, which ensures the long-term survival of the gardens. The commitment of the volunteers is voluntary and great care is taken to ensure that the volunteers do not suffer volunteer burnout, which could endanger the continuity of the entire initiative.

The managing director has the opportunity to reflect on the development of the association within the framework of numerous student and scientific contacts. So, far there has not been enough time to evaluate the work of the association as a whole. The city administration has not yet considered such an evaluation to be necessary. However, financially supported small sub-projects must be billed to the donor and concluded with an activity report, so that a regular evaluation takes place at this level.

# **Future planning**

Food production and ecological sustainability are very important for the city. Hanover is one of the greenest cities in Europe and wants to maintain this status. There are 22,000 allotment plots in Hanover and the city itself has large areas that are still available for food production. For this reason, food cultivation and self-sufficiency play a major role within Hanover's urban society and are an issue for both the administration and the council. This is reflected, among other things, in the fact that the city council decided to develop an "agriculture programme" in 2017.

The association uses existing resources to further disseminate the idea of intercultural gardening in community gardens to the public. Each district, especially if it is a socially disadvantaged district, should be able to initiate such a garden project. However, this is linked to the demand for more staff:

"We really do have this demand that we do not only support gardens, but that we are a social environment. And it is tremendously important to give advice and support to people in this environment."

Occupation and processes of social change



People come to gardening in the community garden with the most diverse previous experiences, interests and intentions:

"We have people who have never had a spade in their hands before and say that they now just want to garden, they just want to try it out. For example, we have people who have had an allotment garden for years and want to limit themselves to community gardening and a smaller bed for time reasons (lack of time due to gainful employment) or physical reasons (e.g. advanced age). We have people who have also intensively fermented in their homeland. Then there are various people who are also interested in horticultural science and then continue their education."

The association is based on the principles of the Urban Gardening Manifesto (2014), which the International City District Gardens Hanover have co-signed. These include participation, justice, fairness, activist orientation and the opening of spaces of opportunity. Behind this is criticism of the capitalist social model and the desire to be able to point out or develop new models of social coexistence. The association sees itself as a community-oriented institution, i.e. it follows the principles of community work. The management takes particular account of the problems and needs with which people come to the association and how they can be supported through different activities in the garden, but also through different experiences of community. Here the great potential of community gardens as places of activity, encounter and experience is shown, which represent an urgently needed alternative or supplement to the offers of the neoliberal performance society. Because people experience a lot of pressure, for example, through experiences fleeing from their home country as refugees, and other situations, such as conforming to the demands of the job centre, the association tries to create a space where people can take a little breather.

"Neoliberal performance society plays a very subordinate role for us, and we intend to continue to keep it that way. The only service that people have to provide is the cultivation of fruit, vegetables or even flowers, so that they use the garden for its intended purpose."

Many gardeners see gardening as a meaningful activity to prevent boredom.

"They work, but not in the sense of an activity covered by social security, but they work in the garden and produce their vegetables or their food. And that can be acknowledged to such an extent that they can tell themselves: "Yes, I have worked." And that gives people a certain self-esteem. Sometimes this is a very strong feeling, sometimes less so. There are people who are principally really in the garden from sunrise to sunset. "

Furthermore, taking care of the communal areas offers the possibility to do something for the community and to derive a positive self-esteem from it. For a group of women, working together in the garden is an opportunity for an unhurried get-together:



"For these women there can be a social pressure to be active and do things for others. It would not be socially acceptable if they simply sat down and had a cup of tea together as this would be seen as idle chatter, but it is accepted that they are outside and do something - so they have a chat while watering the plants together. Watering the plants is an accepted way of spending time because it is for the good of the family or the neighbourhood group who use the garden bed. Because the gardens are in the middle of the high-rise buildings people spending time there are very visible."

In the International City District Gardens, community gardening is consciously seen as an opportunity to support learning effects and individual development:

"I try to interest people in different things or new topics, but I do this more as part of an offer. It is up to them if they want to accept."

Through the common interest in gardening, the gardeners can also get interested in new topics and people. In the exchange with visitors during on-site visits they experience themselves in an expert role, which provides them with a feeling of appreciation. On the horticultural and neighbourhood level, there are many such positive effects around the gardens, where people support each other with small services, e.g. carrying out handicraft activities such as repairs, translation work, accompanying people to city councils or other authorities or leading a group of children.

"For our society as a whole, I think it is very important that we offer people activities like gardening."

In an increasingly virtual and anonymous society, people who are lonely, physically and mentally unchallenged and unable to cope with their daily leisure time can be grounded by gardening. Community gardening enables a cultural exchange between diverse people, so that diversity can be created as a model of living that is compatible with groups, i.e. in an exchange of mutual give and take.

With regard to the diverse social functions that result from gardening in a community garden, Eberhard Irion sees holism as an important supplement to the principle of sustainability.

"The concept of sustainability is based on social, economic and ecological compatibility. But I think that is not enough, as the individual human being him- or herself must be considered even more intensively, but also the interaction between people. I find considering the spiritual backgrounds of people essential and 'holism' implies a strongly person-related way of acting, a respectful treatment of the other person. Holism also means that I have more responsibility towards the system as a whole."

# **Best tip**



"That you keep watching out: Am I sure that I'm not losing anybody? Because it is mainly about working together with other people and treating each other in a respectful way and not running into big group-dynamic problems later due to time pressure. It is about people looking after each other. A mindful, holistic approach towards each another is very, very important. Because if this is missing, the project will fail at a later point."



Knit and Natter: Barnsley, UK

# Claire Craig

Reader in Design and Creative Practice in Health and Co-Director of Lab4Living, an interdisciplinary research cluster at Sheffield Hallam University

This case is an example of a group that developed from the personal initiative of a couple and their interest in knitting and crochet together with a desire to give back to their community. It indicates how occupation can become the focus for the development of a sense of belonging and community amongst a group of people living in a particular area, providing support as well as a sense of purpose for the people involved. Some further details of the group can be found here: https://www.livewellbarnsley.co.uk/Services/1125/St-George-s-Knit-and

Barnsley is a town in South Yorkshire in the United Kingdom located half between Leeds and Sheffield. It has a population of approximately 92,000 people. Barnsley is a former industrial town centred on coal mining and glassmaking. In the 1960s there were 70 collieries within a 15-mile radius of the town but the last of these closed in 1994. The demise of industry has caused significant challenges for people living across Barnsley. Indeed in 2016 40% of Barnsley children were identified as living in poverty and Barnsley was rated as the 39<sup>th</sup> most deprived area in England out of 326.

This is the backdrop against which the following project is set. Knit and Natter is an open group that meets every Monday at a church hall in Barnsley. The group was established 7 years ago by husband and wife team, Gloria and Brian M who recognised a need to create a safe space where people from diverse social and cultural backgrounds could come to meet each other through engaging in a craft group focusing on crochet and knitting. Since it was created, the group has gone from strength to strength. On average a core group of 40-50 people access the group every Monday, which runs between 10.00 a.m.-4.00 p.m. to learn skills, offer each other help and connect with the broader community. In addition to creating a supportive social network the knitted and crocheted textiles created by the group have been used to support premature babies, older people living in poverty, have contributed to a number of international projects in Africa and have raised funds in excess of £5000.00 to support a number of charities.

# Broad description of the group and its development

The two people (G and B) who started the group had a background in textiles. One had worked as a seamstress for a large clothing manufacturer and the other was an engineer in the same factory "so textiles and making were something that



ran in our blood". When G retired, they knew that they wanted to give something back to the community and so immediately when they finished work they spoke to the vicar of their church to ask for permission to use the church hall to establish a knitting and crochet group.

Their son produced a number of fliers, which they sent out to various community organisations. Then, on the first day, they turned up "armed with some balls of wool, crochet hooks, tea, coffee and milk". The group immediately had a large number of people attending: "We opened the doors at 10.00 and stayed until 5.00 to cope with the sheer volume of people who came through the door."

The second week people were already waiting at the door when B and G arrived. Additionally, people were already contributing to the group, bringing with them a loaf of bread, a spare ball of wool, a knitting pattern, no matter how small and despite their own challenges. "It was extraordinary".

Very quickly the group became a social event: morning coffee, lunch, tea. At the same time people began to share their skills around other types of craft work, including card-making and sewing. The occupations of the group expanded as refugees and asylum seekers were able to develop key language skills and in return to share rich cultural insights and experiences. People found support and friendship.

The occupations of the group have further expanded to include annual formal trips and visits for the group. These include trips to Holmfirth, Bridlington and to Wales where they have been to craft shops and events. These are funded with the remainder from the small weekly contributions of 50 pence paid by those members who can afford it, particular helped by the large amount of donations of materials received. Some people in the group have not been out of the local area, and "so the idea of going somewhere different can literally be life-transforming." In addition, the group has become involved in fund raising for charity. They sell some of the garments made at church fairs and organise fund-raising events. The group has given money to the neo-natal unit, to the hospice, to the hospital, and to the church, as well as using funds to buy chairs and tables for the church and nice crockery for the coffee breaks. The group has also bought sewing machines for group members who want to try their skills at dressmaking.

The group has also supported members beyond the immediate activities of the group. For example, when one member was diagnosed with terminal cancer the group came together to enable her to see her daughter get married. "Every single member of our group gave everything they had to make that happen", providing the dress, crocheting the bouquet and contributing money for the food. Such evidence of a "true community" is also shared in the support the group gave to two asylum seekers, including attending their hearings against deportation, and sharing in the loss when this took place.



Since that first meeting the group has run every single Monday. The only days it has not run, is when Christmas and New Year has fallen on a Monday. When G and B suggested that the group could break over Bank Holidays, they did not do this finally because "so many of our members told us that this is when it is most difficult, when loneliness is at its worst." Over the years hundreds of people have attended the group. During any Monday up to 80 people may attend with a core group of 40-50 people. Some stay all day, others just for an hour. The success of the group is measured by the on-going attendance of so many people.

# Who is involved and how do they work together?

The group was founded by a retired couple and is open to all members of the community. All are welcome and participants include refugees and asylum seekers, people staying at the local homeless hostel, people with experience of mental illness, carers needing a space away from their responsibilities, as well as anyone interested in knitting, crochet and crafting.

The group has flourished as all members bring something to contribute and all have something to take away. There is no formal structure (i.e. it is not registered as a charity or social enterprise).

### **Processes of transformation**

The group is seen to operate as a "true community", providing a space where people can come together, learn and share skills, flourish as individuals, but also as a group (community) contribute to the lives of each other and those beyond the group in need of support.

Individuals who live alone or with experience of homelessness, have found support and friendship. Everyone contributes and receives something. "We have watched people flourish – []. It's a real community where everyone cares for each other."

# Occupation and processes of transformation

The group was advertised as a place where people could come to learn how to knit and crochet, so this was key. However, G and B quickly noticed that while people were initially attracted to the occupations offered by the group as well as learning these skills, as group members' confidence grew, they became willing to share their experiences and skills. As a result, individuals learned and shared multiple activities. The processes of learning and developing craft abilities enables individuals to flourish as these are shared with others. "- individuals who started simply by calling in for minutes with few skills are now leading and sharing sophisticated craft abilities with other group members". Learning to knit, for



example, has enabled someone to manage their extreme anxiety. The sharing of skills, and the caring that that entails, enables people to feel that they belong and have value. A sense of purpose and value is further supported as the group works to support others outside the group, for example, through fund-raising for charity.

G and B themselves talk about the growth of their own confidence and sense of purpose as the group has developed in directions and in size that they had never imagined.

# **Guiding theories and assumptions**

G and B comment that they did not begin with any particular vision about where the project might lead. They were interested in using their skills and passion to give something to their community. They see the outcome, "the direction it has moved in and the size and the scale [as] incredible" and a reflection of what can be achieved when two people offer something to the community. They perceive that the group is in part successful because what they had to offer "really hit a keynote with the community. It came at a time when people were searching for something and we simply fulfilled a need. We stepped out, took a bit of a risk."

A core assumption that is evident is that everyone has something to offer, something to share, whether that is a particular skill, something to share to eat, or a smile. There is no judgement of people, their skills or their difficulties. A warm, safe, social space is created where people can feel 'at home', relax and share their stories (as well as their skills) with others.

G and B comment "It just evolved. I think if we had had a fixed plan and tried to fit people into this we would have struggled. I think that the project has been such a success because we didn't have a plan but just offered a space."

## **Key resources and barriers**

The only resource is the church hall where the group meets once a week. Everyone is invited to make a contribution of 50 pence a week towards the hire of the church hall, materials and refreshments, but if someone cannot pay this it is not a problem. The group sees itself as being self-sufficient, mainly through the donations of materials that are made: "The only thing we've received from outside are donations of wool when people have been clearing out cupboards."

G and B are key resources with their passion and skills for textiles as well as their sense that they still have something left to give and a desire to have a purpose after retirement.

The only barriers identified were to do with the number of people attending and resulting limitations of space. Although G and B founded the group the group is



not reliant on their physical presence each week. The group has 'become like a family' and members provide mutual support.

# Sustainability and continuity

G and B do not have any specific plans for the future of the group: "Who knows what the future holds? Our role is not to force or control the group. All we do is to offer a space and as long as the group is needed, we will be here."

# Final message

"Only this. Brian and I are ordinary people in our late 60s and 70s. There must be lots of people like the two of us up and down the country. I hope that what we have shown is that when two people come together with a skill and a passion to make a difference that lives, not least ours can be transformed."



# SENT X 100: Art and culture for wellbeing and social participation, Spain

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Universitat de Vic-Universitat Central de Catalunya (UVic-UCC). SaMIS research Group.

# **Introduction**

Sent x 100 project (www.sentx100.net) aims to guarantee access to meaningful art and culture occupations as a fundamental human right and as a strategy to improve the wellbeing and social participation of users. People with Alzheimer's disease and with mental health issues are participating in the project, which is also focused on the wellbeing and social participation of the caregivers. This is possible thanks to a powerful partnership with art and culture institutions and with the public sector, always working within the capabilities of the participants and communities' resources.

The project is being developed by the Universitat de Vic-Universitat Central de Catalunya (UVic-UCC). UVic-UCC has been successfully developing strong partnerships with prestigious art and cultural institutions in Spain and worldwide, including the Centre of Contemporary Culture of Barcelona, the National Auditorium of Catalonia (Barcelona), the Museum Thyssen (Madrid), Museu de la Pell (Vic), Museu Episcopal (Vic) and the AcVIC Centre of Contemporary Arts (Vic). These alliances form the foundations of the action research project.

The project is developing a new project in Vic (Catalonia), moving from working with one institution to aiming to create an art and culture friendly city for people with Alzheimer disease or mental health issues. This means ensuring that all the art and culture facilities in the city are inclusive.

## **Broad description:**

The core of Sent x 100 project is to guarantee the access to meaningful art and culture occupations; it is a strategy to improve the wellbeing and social participation of the users (Simó Algado et al. 2017). "Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits." (Article 27, Universal Declaration of Human rights). Unfortunately, so many populations are occupationally deprived of this experience, such as people experiencing mental illness or Alzheimer's disease. Traditionally, art and culture centres have been considered elite institutions and have not been aware of their responsibility to become inclusive institutions.



Since its establishment in 2017 at Universitat de Vic-Universitat Central de Catalunya (UVic-UCC), the Sent x 100 project has been successfully developing various collaborations with a number of prestigious art and cultural institutions in Spain and worldwide. It started at the Centre of Contemporary Culture of Barcelona (CCCB, 2017), with people experiencing dementia. It continued at the National Auditorium of Catalonia (NAC, 2018), with people with Alzheimer's disease. The project is now being developed at the Museum Thyssen in Madrid (MT, 2018-2019) with people with mental health problems. Consultation work has been done for Winnipeg Art Gallery in Manitoba, Canada (WAG, 2017).

A new Sent x 100 project has started at Vic city (VC, 2018-2019) with people with Alzheimer's disease. Rather than being based in a collaboration with one institution it is evolving into a project to develop an *Art dementia friendly city*, as it involves three art and culture institutions (Museu Episcopal, Museu de l'Art de la Pell and the AcVIC Centre for Contemporary Culture), two local orchestras (EMVIC and UVic-Inclusive orchestra), one Cine-Forum and four artists.

Participants are enjoying art exhibitions (Centre of Contemporary Culture of Barcelona-Museum Thyssen-Vic City) or listening and performing music (National Auditorium of Catalonia-Vic City). All the institutions develop adapted interactive sessions. Art pieces are selected by the educators and occupational therapists taking in consideration the participants' needs, personal interest/values and previous experiences (Centre of Contemporary Culture of Barcelona-Museum Thyssen) generating dialogues and connections between the participants' lives and the art pieces. At the National Auditorium of Catalonia musicians perform for the participants music pieces that are meaningful for them, enjoy the national orchestra performing for them and then participants perform music themselves with the support of a music-therapist. At Vic, one person with Alzheimer's disease will become part of the UVic-Inclusive orchestra, that will devote the spring concert to this population.

Universities need to be at the forefront of social transformation. They have knowledge about contemporary challenges and how to solve them and they have to fulfil the democratic commitment expressed in their core value statements. The project is being developed by the UVic-UCC through the Mental Health and Social Innovation (SaMIS) research group, with the support of the Chair of Mental Health (UVic-UCC). The SaMIS research group is composed of 36 researchers. It is based on a strategic partnership between UVic-UCC, Consortium Hospitalarium Vic, Althaia Health Network and Osonament, the centre delivering community mental health services. They are responsible for the mental health services of the Central Catalonia region. The Sent x 100 team is composed of three occupational therapists/occupational scientists (OT/OS, Jessica Garrido, Penelope Aguilera and Salvador Simó), with the support of two social anthropologists (Xenia Duran, Laura Marin). The project is working in partnership with the art and culture



centres, collaborating with their staff who are usually educators (CCCB, Museum Thyssen) or music therapists (National Auditorium).

The action research project was initially generated between Universitat de Vic-Universitat Central de Catalunya (UVic-UCC) in conjunction with the CCCB. CCCB contacted the occupational therapist/scientist project leader as they were recommended by Museum Thyssen. CCCB was already developing visits for people with Alzheimer's disease and were really interested to develop an evaluation to understand its impact. A mixed methods research project was designed by UVic-UCC to match this goal. From this first experience with CCCB, new action research projects were designed and developed by UVic-UCC in partnership with the National Auditorium of Catalonia, the Museum Thyssen, Serralves Foundation and with the Vic city council (again in partnership with CCCB).

#### Who is involved and how do they work together?

The project has been made a reality thanks to the art of partnership. The partners, who are co-ordinated through the Universitat de Vic-Universitat Central de Catalunya are: 1) University: Universitat de Vic-Universitat Central de Catalunya. 2) Art and culture institutions: Centre of Contemporary Culture of Barcelona, National Auditorium of Catalonia, Museum Thyssen (Madrid), Museu Episcopal (Vic), Museu de l'Art de la Pell (Vic) and the AcVIC Centre for Contemporary Culture, EMVIC Orchestra, UVic-Inclusive orchestra, Vic Cine-forum. 3) Public sector: Vic city council. 4) Health institutions: Mental Health Centre La Latina among others. 5) Users associations: Association of families of people with Alzheimer of Osona AFMADO. 6) Mass Media: Canal Taronja TV, El Vigata among others.

Regular direct and online meetings are very important. Developing work in common through the following means activates and empowers the partnership: 1) Publishing in scientific journals. 2) Presenting the project at scientific congresses. 3) Presenting the project to the general community. 4) Training the professionals of the health centers about research.

# Target population: people with Alzheimer's disease and mental health issues

Participants (the majority with Alzheimer's disease or mental health issues) are contacted via local day centres, mental health centres, nursing homes, etc. CCCB and NAC make direct contact with the participants themselves. In Madrid, the project with the Museum Thyssen has a strong partnership established with the Mental Health Centre la Latina, in collaboration with Ana Abad (occupational therapist/occupational scientist). In Portugal, there is a partnership with Politecnico Porto lead by Antonio Marques and Sara Sousa (occupational



therapists/occupational scientists) from the Hospital de Sao Joao (a mental health institution).

In Vic the project has directly contacted the service user and family members organization AFMADO. Political contacts are very important to develop the project at a city level. The city council major for culture was approached and there is a collaboration work with the cultural department of the city. The social affairs department is also involved to facilitate the participation of people with dementia. Thanks to this, a powerful network has been created with the local health and social services working with people with Alzheimer's disease. Initially planned for the city of Vic, the program is now embracing people with dementia from the province.

# Occupation: process of change

As occupational therapists/occupational scientists are leading the project from UVic-UCC and they are also part of local teams in Madrid it is an occupation-based project. The project departs from a clear case of occupational deprivation: Alzheimer's disease and mental health issues do not prevent people from enjoying and engaging in art and culture-based occupations. The project is inspired by an occupational justice (Galheigo, 2011) and Human Rights perspective. Occupation is embodied in the form of art/culture. Participants enjoy painting, music, visual art, sculptures and dance, and make artistic performances such as music. The ultimate goal is to create healthy, inclusive and sustainable communities (Simó Algado, 2012; Simó Algado & Townsend, 2015). Related knowledge from neurosciences research, citizenship theories, social determinants of health, mental health and recovery, sociology, philosophy and research are taken into consideration.

Occupation takes various forms in the different art and culture institutions. CCCB organizes visits for people with Alzheimer's disease to current exhibitions. The topics can be very diverse. Five to six meaningful art pieces are selected to begin a dialogue with the audience. Adaptation to the needs of the audience is a key aspect. The sessions take place on Mondays when the centre is closed to the general public. The Centre is adapted to the principles of universal design. Audiovisual stimulation is carefully adapted for the visits diminishing both stimuli. Time duration is controlled to prevent users becoming tired and seats are available during the visit. Caregivers and family members are always welcomed to the session.

At the National Auditorium of Catalonia, the visits have three parts. In the first part, two musicians from the National Orchestra of Catalonia play for the people with Alzheimer's disease and perform music that is familiar to them. In the second part, they listen the complete National Orchestra of Catalonia performing for them.



In the third part, they play music themselves accompanied by a music therapist. Caregivers and family members are always welcomed to the session too.

At Vic, the programme is organized throughout the year. Sessions include visits to art and culture centres at Museu Epsicopal, AcVIC Centre for Contemporary Art and Museu de la Pell. Visits are guided by an occupational therapist or an educator. Again, five to six pieces are selected and a dialogue is developed with the audience. The main difference from the CCCB programme is that at the end an artist performs (music, dance...) for the people with dementia. Caregivers and family members are always welcomed to the session too. Students from the occupational therapy degree programme from UVic-UCC take part in the sessions as part of the Service-learning methodology. Another novelty is that one person with Alzheimer's is welcomed to the UVic-Inclusive Orchestra and will perform for people with Alzheimer's during the spring concert. Activities directly proposed by the users and family association have been included in the program.

In Madrid, the session at Museum Thyssen are led by one educator from the museum, Alberto Gamoneda. Ana Abad, an occupational therapist/occupational scientist, is coordinating the project from the Mental health centre La Latina to develop regular visits. The visits take place during the usual museum timetable, normalising the experience and avoiding creating a separate program. In contrast with the intervention with people with dementia where the museum is opened especially for them, to avoid overstimulation and to be able to control all the audio and visual stimuli.

Two good examples of the power of transformation through occupation are the projects developed by the Centre of Contemporary Culture of Barcelona and at Vic. Research not only revealed the positive impact on the wellbeing and social participation of the people with Alzheimer's disease and the caregivers but a positive impact on the educators, who found their job to be more meaningful as a result. Most importantly, the project is changing the working approach of the cultural centre itself. Thanks to the project, they have understood the need to be inclusive for all the community and now are trying to include people from the Raval neighbourhood. Raval is an economically deprived area whose inhabitants were not participating in CCCB activities.

A second example is Vic. The project is evolving from based around intervention in a single institution to Vic becoming an Art and Culture Friendly dementia city. All the art and culture institutions and centres of the city are transforming themselves to be inclusive to the people with Alzheimer's disease and their caregivers.



#### **Evaluation**

Mixed research projects have been developed led by SaMIS in partnership with the art and culture institutions. Research has been important in measuring and understanding the impact of the project related to the wellbeing and social participation of the users and the caregivers as well as the impact on the art and culture institutions (Simó Algado et al., 2017). It is important to note that the research was not just focused on the people with Alzheimer's disease or mental health issues but included describing benefits for everyone.

# **Funding and sustainability**

Origins of funding are diverse. The intervention project is already incorporated into the yearly programs of the museums/art centres (Centre of Contemporary Culture of Barcelona, Museum THyssen, National Auditorium of Catalonia), so its sustainability is guaranteed. The Centre of Contemporary Culture of Barcelona and the Centre of Contemporary Culture of Barcelona are developing the visits out of funding from their education departments. The intervention at National Auditorium of Catalonia is funded by a Catalonian government program named Apropa cultura (Bring culture closer). A formal agreement has been signed with the Vic city council to guarantee the project over future years. The project is not expected to generate incomes. All the activities are completely free for the participants and the health centres.

The research dimension has one cycle, and its funding also has diverse origins. In the case of the Centre of Contemporary Culture of Barcelona the institution funded itself. Apropa cultura has funded the research at National Auditorium of Catalonia. Museum Thyssen has their own funds from the research group SaMIS which are both connected to doctoral students.

The project has been disseminated through a web page, participation in congresses and with scientific articles, but also, and especially important since it is about inclusion, through contact with mass media to reach a wider public. For example, in Vic, there is a close collaboration with the local TV, radio and newspapers.

## **Future planning and challenges**

The intention is to spread the project to international and national museums or art centres that have not yet developed inclusive policies and to establish a knowledge hub partnership with the ones already developing similar projects. Many art and centre institutions are still 'closed' to people with dementia or mental health users.



The main goal is moving from an approach based around single institutions, to an art and culture friendly city approach. To achieve this the strategy is to work in partnership directly with the city councils as has happened in Vic. New contacts with the Catalonian government have been made for the project's expansion and to be able to build art and culture friendly cities across the region.

There are several challenges. The main limitation is the unwillingness of certain art and center institutions to embrace a diverse population. Building alliances is complex. Partners need time to develop mutual knowledge and confidence. Each institution has its own culture, for example, university culture is different from cultural institutions or from the city councils. Moving from a single institution focus to a city focus as has been done in Vic has increased complexity.

Universities are still too attached to their platonic understanding of reality, still too distanced from contemporary health and social challenges. Bureaucracy processes are not always easy to navigate, universities are still not fully ready to develop action research projects at the community level, as they are coming from more traditional approaches to university located research. Funding is always difficult to achieve. The challenge is to encourage universities to become really focused on creating knowledge that directly improves the wellbeing and social participation of the population, especially those facing illness or social exclusion. Action research projects are key for this purpose, creating knowledge focused on social transformation (through occupation).

# **Best tip**

Art and culture are meaningful and universal human languages.



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# APPENDIX 1: Interview outline

We present below the interview schedule as developed for this research project. We provide it here as a useful guide for those wishing to contribute a case to this resource.

# **Openings**

In this interview, I would like to focus on gaining an in-depth description of a project you have been involved in that is an example of occupation-based (by which we mean activity or action-based work for...) social transformation. As we have discussed we plan to use this data to write the project as a case example. To do this, I will ask a few open-ended questions and will probe for further detail as we engage in conversation. (Note to interviewer: throughout the term 'project' may be interchanged with initiative, programme or service etc depending on the particular project)

# **General information**

1. To begin, would you please give me a broad description or overview of the project.

# Prompts:

- Title of the project- duration starting date closing date or ongoing
- Partners; who was/ is involved

# **Evolution of the project**

2. Thinking about your project example, can you tell me about the early stages of the project?

# Prompts:

- How was the idea initiated, how did you become involved, and what were the first steps in moving from the idea for the project to actually starting the project.

## Building a sustainable partnership

3. Can you please describe which partners were or are involved in the project, and what it is you hoped or hope to be working towards?



## Prompt:

- What is your partnership policy? Who are your partners outside the immediate project group? How do you involve them? Are they from the public, civil and/or private sector?
- 4. Can you describe how the project has unfolded?

# Prompts:

- Time frame, how community/group involved, steps, management, funding etc.
- Funding: How did you get your funding? Was it enough? If not, how is it affecting the project development? Do you have different sources of funding? Does the project itself generate income?
- Is the project completed or on-going?

# **Achievements**

5. What has the project been able to achieve?

# Prompts:

- Approach to evaluation, impact of project

### <u>Challenges</u>

6. What were and are the barriers you faced in carrying out this project, and how did/do they influence how that project was carried out and its outcomes?

## Theoretical underpinnings

7. Reflecting on the project you just described that was developed, in what ways is/was occupation interwoven in the project?

#### Prompts:

- Method for collaboration, intended outcome, etc.
- Would you consider this project as an example of occupation-based social transformation and why?
- 8. What theoretical perspectives and/or concepts guided how the project was developed, enacted and evaluated?



# Future perspectives

9. How do you see the future of the project?

# Prompts:

- approaches to sustainability
- 10. "Golden tip- hundred-to-one shot"

What would you advise colleagues who wanted to start a project like this?



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