

# Small Supports

## A Paper to Challenge and Inform Transforming Care Partnerships



*Small Supports is an informal partnership between:*

**Beyond Limits**

**C Change**

**NDTi**

**Positive Support for You**

*Working with:*

**The Local Government Association**

**NHS England**

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NDTi in Partnership with Beyond Limits, C Change, Positive Support for You,  
LGA, NHS England.



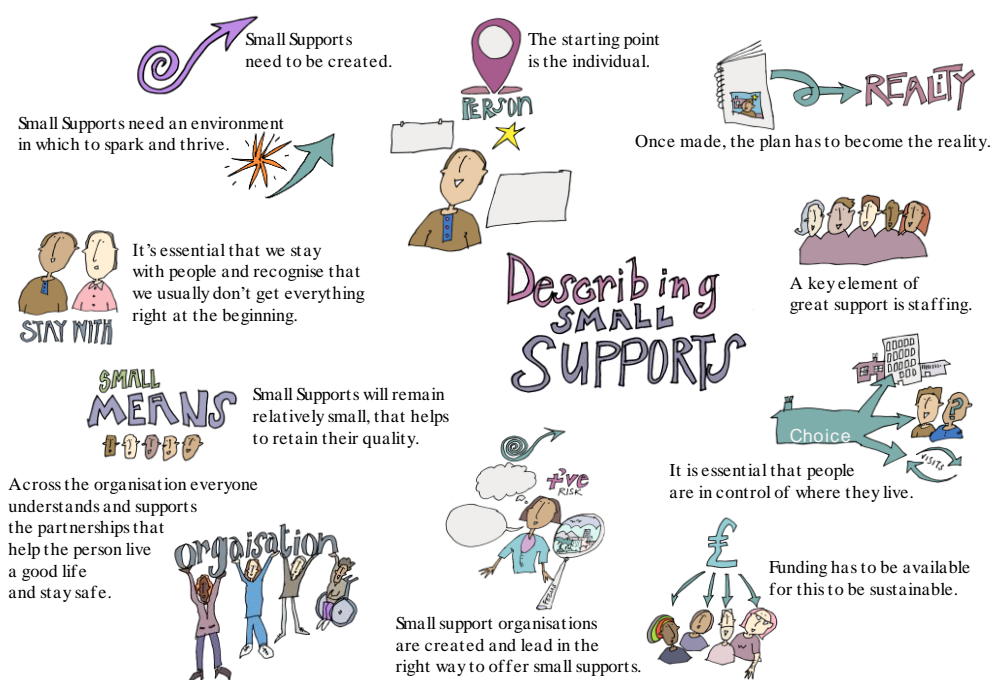
## Summary:

This paper thinks about people with learning disabilities and /or autism who are living in secure settings (hospitals and ATUs).

We are **not** saying what we think people with learning disabilities or families should do. We have written the paper to challenge and help Transforming Care Partnerships. This means that sometimes we have had to use 'jargon' and it is quite long.

The key things that we are saying are that:

- People should be living in the community. They should be choosing where to live, their supports staff and how their support people behave.
- This includes people who sometimes have a reputation for being hard to support. This might mean that they have spent time in secure hospitals or other locked places.
- This means that some people need great support organisations. Where these great organisations do not exist now we need to help them grow.
- The system (how we choose and pay for services) can be made to help new great support organisations to grow.
- To help new organisations grow we need to find great people to run them then we have to help them to set up their organisation and find great staff.
- It takes time to make support great. We have to keep listening to people and families, keep planning and know what we will do if there are difficult times.



## Introduction

For some years a new informal group of support organisations has been evolving. These organisations are committed to supporting people with learning disabilities, mental health issues and autism and who are identified as having complex support needs because of their behaviour, forensic or offending history. Often the people supported have experienced a string of placements in inappropriate, segregated, out of area, secure settings. Usually, these placements failed or broke down not because of the person but because the service was wrong. The impact on individuals and their families is huge. Large amounts of scarce public resources are invested.

These support organisations, which we will refer to as '*Small Support*' organisations, have been developing quietly, supporting each other and with the active assistance of a handful of local health and social care commissioners. Each is different, but with some core consistent approaches and characteristics.

Within the NDTi and NHSE, we wanted to understand why these *small support* organisations were growing in some places but not others and why there were so few of them compared to the number of people seeking highly personalised, highly skilled local support. So, we went on a field trip, met some people who inspired us and began asking questions about what great looks like and what local health and social care organisations could be doing to facilitate the development of great new small support type organisations.

A loose partnership evolved between C Change, Beyond Limits, Positive Support for You, the NDTi and NHSE. We began trying to draw together the learning and share it. Leeds City Council and Birmingham and Solihull NHS Trust began working with us with the specific aim of changing their local commissioning and planning systems to encourage and use small supports. The LGA then joined us with funding to work with six Transforming Care Partnerships to dig into what was happening now, the impact of this and explore what could be put in place to assist *small supports* to grow.

This work isn't suggesting that there are not some great larger support organisations or micro-enterprises or that everyone who wants assistance will do it through a formal organisation. It is saying that for there to be a choice there has to be a real choice. And it is emphasising what we found about the way in which these types of organisations generate real successes with people who are often failed in more traditional settings.

In pulling together this paper we are not trying to write a definitive guide or tool kit (there are too many of those already) but to try and offer a challenge and some answers to local health and social care organisations about what they could do to encourage and support the growth of small support organisations in their patch.

This paper is intended to provide a snapshot of where we are in January 2020. The programme is ongoing, and the work is slow. Slower than we anticipated but we have to remember how long it has taken 'the system' to get to the place it is. A small evaluation is

ongoing as is activity in sites. Action is being taken, systems changed and some new small support organisations beginning to grow.

### **A brief note on our language**

- When we say 'people' we mean anyone who might want to be supported by small support organisations. Our focus has been on people with learning disabilities and autism who have complex support needs based on their behaviour towards themselves and other people. This includes people with forensic, offending and challenging histories. People included in Transforming Care. Sometimes we use the phrase 'people with hefty reputations'.
- When we say 'families' we are including any family, friends and community members who the person has chosen to be in their life.
- A 'small support organisation' might be not for profit (third sector, Community Interest Company, etc) or it might be a business.
- 'Professionals' is our shorthand for the range of specialist roles.
- 'Commissioners' are anyone in commissioning or procurement roles.

### **A request**

We think that *small supports* is a good way to describe the work that we and others are doing. It's only a name so not as important as the detail but we know that if other people start talking about things as being 'small supports' when they aren't then our task becomes more difficult.

# Describing *Small Supports*

## Characteristics of *small support organisations*

In working with and getting to know a number of these organisations, we have sought to draw out what they have in common. Whilst each is unique in the business model, how it started and how it runs, the essence of what matters to these organisations is consistent.

*The starting point is the individual. This means that:*

- From the first steps the individual, and their family, have to have as much control as possible and everyone needs to commit to this control growing
- Person-centered approaches to guide a conversation are used to deliver the best plans. The starting point for planning is the person's aspirations and needs. Conversations about support, behavioral and risk are essential but follow later
- Everyone involved should expect radical changes in aspirations, plans, and supports in the first couple of years. This might have a significant impact on choices made in, for example, housing.

*Once made, the plan has to become the reality. For this to happen:*

- Everyone needs to understand that supports can be a platform to people having a life – they are not the life
- Making compromises is when things start to go wrong

*A key element of great support is staffing. This means that:*

- Staff should genuinely be recruited around/by the person (this includes not moving staff who are failing/unneeded around services)
- Staff should not be in lots of people's teams
- It is likely that training delivered in more traditional organisations may be of little use and may have to be undone
- Remembering that staff are not a substitute for friends, community peers, coworkers, and neighbors

*It is essential that people are in control of where they live. This means that:*

- People choose where they live
- People choose who, if anyone, they live with
- People are tenants, owners or living with family members
- Everyone visiting the person's home remembers that they are a guest

*Funding has to be available for this to be sustainable:*

- All individual services need to be individually funded
- Funding is controlled and used individually

*Small support organisations are created and lead in the right way to offer small supports.*

*This means that:*

- There is a committed leader/leadership team who understand how to make an organisation work in a way that supports and does not compromise individual rights and control
- Leaders know and regularly engage with everyone supported
- There is leadership and staffing who understand and work positively with risk
- Funding is sustainable
- The organisation knows and focuses on its community

*Across the organisation everyone understands and supports the partnerships that help the person live a good life and stay safe. Partners are likely to include:*

- Family and friends
- Community members and neighbours
- As needed by the individual, the police, courts, fire services, etc.
- As needed by the individual specialist supports from across health, social care and education.

*It's essential that we stay with people and recognise that we usually don't get everything right at the beginning. This means:*

- We should expect changes and establish ways of learning that support this
- When things go wrong everyone should be involved in thinking about and understanding why. Asking a clinician or outsider to recognise and solve the problem is unlikely to be helpful
- By being present in the person's life, the most senior people in the organisation will help to spot potential and address existing issues

*Small Supports will remain relatively small, that helps to retain their quality. Thinking about size:*

- The focus of the provider is less likely to be people with a particular label than people wanting a particular style of support
- A good indicator of sustainable quality is the ability of the most senior people in the organisation to know the people supported properly
- We suggest that a new provider should not seek to grow beyond supporting a maximum of 5 people in the first year and question its ability to support more than, a total, of 30-50 people well.

*Small Supports need an environment in which to spark and thrive. In this environment:*

- There is a recognition that many current services are failing, and the investment made in them delivers poor outcomes for individuals
- There are 'social entrepreneurs' who understand (are probably part of) and are frustrated by existing services
- There are commissioners who understand what's wrong, who are committed and know how to use their power to help create what is right
- Finances must be approached flexibly
- There is a shared recognition that it takes time to get things right

*Small Supports need to be created. For this to happen:*

- There needs to be a small group of identified people to work with and to develop the organisation around
- Commissioners have to want to work in partnerships outside of the usual practices of procurement
- Funding has to be available to get the provider started. This will be saved against individual support costs

There is a summary graphic on the next page.

In the work, we have tried to use conversations and examples to describe small supports with the best descriptions often emerging in answer to questions. That won't work here so we needed to offer a description. After reading this description please be mindful that:

- It is based on real work by real organisations. Each organisation is different, each will have different approaches, strengths, and weaknesses;
- We are not seeking to offer some form of rigid definition, it's a description to encourage conversation and understanding;
- We are not seeking to 'own' the idea of small supports.

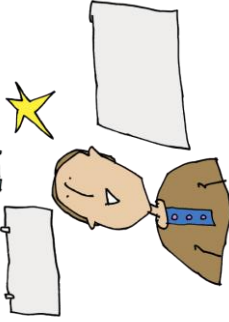
That said, we would suggest that if people disagree with anything we say here they are asked to justify why and, most importantly, remember that it is the people using services who live every day with each compromise made.

Small Supports need to be created.

Small Supports need an environment in which to spark and thrive.



PERSON



The starting point is the individual.



REALITY

Once made, the plan has to become the reality.

STAY WITH



It's essential that we stay with people and recognise that we usually don't get everything right at the beginning.

# Describing SMALL SUPPORTS

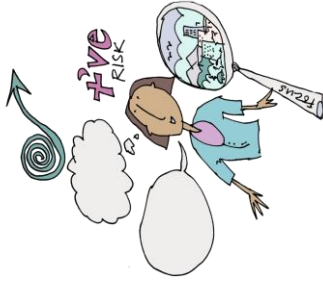
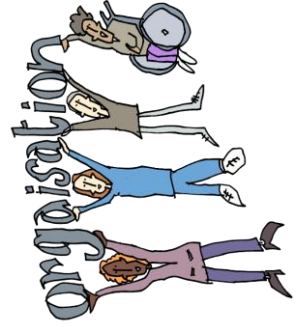


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SMALL MEANS

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Across the organisation everyone understands and supports the partnerships that help the person live a good life and stay safe.

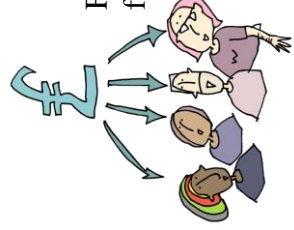


Small support organisations are created and lead in the right way to offer small supports.

Choice



It is essential that people are in control of where they live.



Funding has to be available for this to be sustainable.



# What Can You Do....?

## Understanding the Outcomes of Now

Before we began thinking about what could be different we tried to understand what is happening now and its impact on people, families, and services.

This work was led by two of our team who brought as much independence as possible to the conversation. They had no involvement in or commitment to any plans or decisions that had been made. Both brought a deep understanding of working with people and within systems. Conversations with individuals and families took place without any local 'professionals' in the room.

It is important to have conversations with:

- People who are being supported within the current system. This should identify and include both people who have had positive and negative experiences;
- Families of people who are within the current system. This should identify and include both families who have had positive and negative experiences;
- Support workers;
- Process managers and commissioners.

We choose to ask three very direct questions that are equally open to all participants:

- What are the challenges?
- What is working well?
- If you had a magic wand, what would you change?

Of course, everywhere will have differences but these were some of the key themes from responses to our questions:

### What are the challenges?

- Lack of ambition
- Loneliness and a lack of social inclusion
- Lack of sustainability
- Lack of choice and involvement and Information about possibilities
- Lack of coproduction, advocacy and an understanding of people's rights
- Fear of ATUs
- Poor quality services
- Poor liaison across support services
- Lack of forward planning and prevention
- Recruitment and retention
- Funding processes
- The time it takes
- Trauma
- Lack of monitoring by commissioners

### **What is working well?**

- When people live independently with just enough support
- Good advocacy
- When support enables people to do the things they want
- Approachable police support
- Great support staff where there are strong relationships
- Small services and when people live in own homes
- Relationships
- When we think outside the box
- Life outside hospital
- Some good providers

### **If you had a magic wand, what would you change?**

- Information about and. choice of providers
- Financial leeway
- Access to housing and control over who comes into the home
- Better contracting
- Don't admit people to hospitals
- Involving and respect families
- More freedom, recognising people as people
- Ability to control and change own environment
- Continuity of care
- Support for staff
- Relationships and friends
- Meeting recognised needs without having to fight
- Dedicated autism support
- Stop over-medicating
- Early interventions
- Ensure providers deliver what they say they will

In our view, delivering the changes that peoples' experiences and aspirations demand cannot be done through small changes and more of the same.

# Creating Local Change

Thinking and working with local areas about developing *small supports* we met interested and committed people. Some localities are proving able to deliver change and some are not. We have tried to identify the characteristic that hinder and promote change.

## Local characteristics that hinder change

- Those in leadership and deliver roles do not have and demonstrate a strong belief in and commitment to people living meaningful lives in their community
- Those in leadership and responsible officer posts do not have the time or inclination to develop an understanding of the needs and aspirations of the people or how great supports works
- There is a lack of dedicated time – both within the week and across the weeks
- Those responsible do not have either a role with the necessary authority or an understanding of how to achieve change without authority
- There is a lack of experience of leading creative change
- There is a lack of support, engagement and checking from senior managers.

## Local characteristics that promote change

- People are brave
- A team of people are interested in and given responsibility for developing small supports
- Those involved actively listen to and learn from existing small support providers wherever they are
- There is knowledge of what great looks like and an aspiration to achieve it from a range of partners
- Those responsible have time both within the week and across the weeks
- People in the most senior roles are informed and actively engaging
- There are targets focusing on the development of small support providers, the number of people supported and the quality of that support

## Things to focus on to create local change

Individual funding:

- Ensure that arrangements are in place that deliver easy to access, sustainable individual budgets
- The availability of individualised funding and the small support organisations commitment to using it with the person is probably more important that what it is called and where it comes from

Funding to the person's changing needs:

- Ensure that funding arrangements allow for the cost of transitions and fluctuating support needs
- Think about the availability of contingency funds

- Ensure that funding arrangements are in place that enable work for small organisations – this includes payment for transitions activities, payment in advance/on time. The availability of contingency funds

Enable the development of small supports organisations:

- Ensure that local commissioning and procurement systems actively encourage and enable small support providers
- Putting in place advice and support to people establishing small support organisations – both business and third sector
- Seek out or make available grants to enable small supports organisations to develop
- Walking alongside people and small supports as they plan and act together

Seek out people to create and lead small support organisations

Seek out and support housing options

Activity seek out people to use small support providers

Engage with and seek the active support of health and social care professionals:

- Promote positive risk strategies

Understand and support what enables everyone in the process to become and remain engaged:

- Be brave and encourage bravery
- Take positive risks and explore what is and is not working
- Understand how time is experienced differently by different people. What feels like a normal pace of change for workers within the system is likely to be frustratingly slow for people, families and developing organisations.

## A Conversation About Risk

Unlike many social care, or support organisations, *small supports* organisations recognise that risk is a key feature to be accepted and lived with. The nature of the people's experiences, and the complexities of their lives, and the trauma they have suffered in the past, means that entirely eliminating risk is neither possible nor desirable.

For everyone, it is essential that we start with the person and their aspirations, but it is also essential that we are honest about challenges.

In the work that we have been doing, we have looked at what makes support successful.

Drawing on what has been learned from existing *Small Supports* organisations, we have ascertained that the following risks need to be considered, worked through, and contingencies agreed with a multi-agency approach.

### Thinking about the person:

What are the issues that might trigger experiences or behaviours that have previously led to them being put into a hospital or ATU settings?

- Approaches that are sensitive to them, the environment, sensory, emotional and post-trauma needs should be built into the service and support plan design. Agreements with individuals and families in advance can enable the person to take control over things in a pre-emptive manner, and shared agreements for contingency planning is essential. Consider the involvement of health, social care, fire, community support, police and legal in a shared plan.

What are the risks to the person if their home and support breakdown?

- Balance the desire to maintain things, against getting the right support and temporary change in the environment if needed. *Small supports* organisations on the whole work to sustain the person's support even where huge challenges arise, but also need to be heard when the person appears to need different support for a time, such as to rebalance meds and mental health.

### Thinking about the support staff:

*Small supports* organisations operate with a highly intense level of support, and teams built around each individual. By nature, there can be a high level of stress in the role, with the flip side of the opportunity to work really closely and create bonds with the individual and surrounding team. Risks to the workforce are burnout, stress and physical impacts such as injury.

Small supports organisations have built a range of approaches to induction, training, and models of staffing from using professionally trained nursing staff, to building teams based on shared interests with the person being supported.

Contracts need to recognise the unique type of support staff, build in contingencies to protect in the face of turnover, and support organisations to reward and train their support staff.

### **Thinking about the wider System:**

Partnership working is key, and breakdown is most common where there is not a true partnership

Partners include people being supported, their families, local community, health and social care teams, commissioners, local services such as police and fire brigade and neighbours.

The greatest risk to things not succeeding is when the shared vision and mutual support breaks down between any one or two of these different parties.

The risk associated with legal challenges, community incidents e.g. fire and complaints from local residents are high. But the *smalls supports* organisations recognise that the risk to the person and their loss of human rights is higher and that over time, periods of stability are built, and risks fall and rise. The greatest successes are where everyone works closely together at a high rate of trust, honesty, and openness.

# **A Reflection on Attracting New Support Organisations. Questions to Ask About Why People Might Want to Become Small Support Leaders**

## **Background:**

As with many other areas of service development, Transforming Care and its predecessors have triggered conversations about, and action focused on a perceived need to develop 'the market'. Usually, this meant seeking to grow or replicate what was already there. Occasionally this has included a desire for something different. However little seems to have changed – we haven't seen the blossoming of the sort of individual supports that people have been asking for and which we know can work.

## **What we did:**

To try and understand why most market development activity has failed and to identify a different route we choose to challenge our thinking by using some effective marketing questions.

We thought as two sites together and then as a group that included national leaders. It is important to remember here that our conversation was not about transforming or developing all services, it focused just on small supports.

## **The past:**

Transforming Care recognised the need to offer people with hefty reputations access to very different support and sought to do this by stopping or at least reducing the commissioning of long-stay beds and instead seeking a range of skilled, flexible and responsive support providers, working in (not alongside or apart from) people's communities.

The process used for achieving this change was very similar to that following Winterbourne View and focused on high-level market analysis, mapping and planning, the development of policy guidance and tool kits and understanding what was currently available and open for development.

There have been some conversations about what people want. Some changes were made to local commissioning and procurement processes.

As a result, we have seen some good local development that has had a positive impact on a few people's lives but for many other people this has meant the growth of large providers who work on but not in local communities, a greater involvement from distant funders<sup>1</sup>, more institutions and more placements.

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<sup>1</sup> Here we mean hedge funds and corporations

## **In seeking to engage and inform people who might set up new small support organisations, the questions we asked ourselves and our answers<sup>2</sup>.....**

### **What do we want people for?**

To bring their passion and life experience to helping people have a good life  
To be bold and risk positive enough to set up the new supports that we need  
To have the creativity, agility, and flexibility to support twenty different people in twenty different ways to be sustainable

### **What are they likely to already know?**

How to support people well<sup>3</sup>  
How to lead – working with people to achieve the best outcomes  
How great teams (perhaps organisations) work  
How to spend money wisely  
What great community and networking looks like

### **What do they want to know?**

What are they getting into (thinking about people, businesses and systems)  
What are the risks and how these can be minimised or worked with  
What people (including statutory organisations) are expecting of them  
Who has done this before and what good looks like  
What will their responsibilities be in, for example, registration, financial reporting and working with people under legal constraints  
How to turn their ideas into a sustainable organisation/business

### **What are likely to be the perceived barriers?**

Risks around individuals and the organisation<sup>4</sup>  
Perceptions of local authorities and health organisations as partners and commissioners<sup>5</sup>  
The pressures of establishing, leading and sustaining a new organisation  
The ability to recruit people  
Their perception of the skills they have now and might need  
Personal barriers

### **What might be in it for people establishing a small support organisation:**

Freedom, autonomy and the ability to make decisions  
Leading an organisation where there is real and sustained demand  
Being able to make a positive impact  
Investing in and contributing to their community

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<sup>2</sup> We are not suggesting that these are all the answers or necessarily the right answers – they are simply ours

<sup>3</sup> This includes believing that 'difficult' people and families aren't really difficult

<sup>4</sup> Including what will happen if the Trust/LA change their approach or policy

<sup>5</sup> Including getting paid on time



Funding flexibility

**What are the likely characteristics of people who might establish a small support organisation?**

Driven, resilient, confident, charismatic  
Sense of justice, caring, ethical  
Brave (a history of taking positive risks)  
Creative

**What are the possible demographics of people who might establish a small support organisation?**

Currently or previously working in or around services  
Currently or previously connected to people using services or families  
Unhappy or uninspired by what they are doing  
Possibly not job hunting  
At a point in their lives where they can invest time into doing something very different

## **A Reflection on Attracting New Support Organisations**

### **What to say**

Based on everything considered so far .....

**What are the key messages that we need to be giving?**

This is a small support  
This is who we think you are  
It is possible to establish a new organisation  
We are there for you, we will listen, we will stick with you  
We are addressing what we have got wrong in the past

**What are our likely tactics and tools?**

Target people in the demographic groups identified – communities of practice, family groups and organisations, provider organisations  
Target existing small organisations who might want to change  
Show the support that is available (including grants if possible)  
Show stories with practical details  
Social media  
Use a virus approach – get people we know to talk to people they know, etc. Ensure they have easy information to share  
Find opportunities to talk with people

## Useful Links

Beyond Limits <https://beyondlimits-uk.org/>

C Change <https://c-change.org.uk/>

Positive Support for you <http://www.psforyou.org>

NDTi <https://www.ndti.org.uk>

Thinking small: <https://www.ndti.org.uk/blog/think-small-act-small>

Transforming Care: <https://www.ndti.org.uk/blog/transforming-care-what-good-could-look-like>

Human rights and services: <https://www.ndti.org.uk/blog/people-are-not-inherently-vulnerable-the-situations-they-are-placed-in-make>

British Institute for Human Rights <https://www.bihhr.org.uk/Pages/Category/human-rights-in-public-services>

Useful information for the LGA: <https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/transforming-care>

Useful information from NHS England: <https://www.england.nhs.uk/learning-disabilities/care/>

BL/Small Supports/February 2020