



Co-producing the Needs Based Grouping explainer leaflets

Background

The Tavistock and Portman NHS Foundation Trust (T&PFT) is the provider of child and adolescent mental health services in Camden and is the host organisation of the National i-THRIVE Programme Team, working to implement the [THRIVE Framework for system change \(Wolpert et al., 2019\)](#). In 2017, the four key priorities for Camden were implementing 'Getting Risk Support', setting up 'Getting Advice and Signposting' appointments, having robust systems of clinical oversight and review for cases in 'Getting Help' and 'Getting More Help', and embedding shared decision making across all of the THRIVE Framework needs based groupings.

Over the past four years, this work has endured and the T&PFT as an organisation have embedded the THRIVE Framework into many areas of their clinical practice, such as within 'CareNotes'; the electronic patient record system used for clinical notes and records. One feature of CareNotes is the creation of Care Plans, which are created as part of the routine patient record management and treatment plan, and are shared with families. Within the Care Plan, families are able to gauge an understanding of the details of the help and support they have chosen to engage with; including the needs based grouping that their plan of care most aligns with.

Why develop the leaflets?

As part of ongoing work in South Camden to engage with service users via the Patient and Public Involvement (PPI) team at the T&PFT, the team received feedback from a service user participation event held in 2020 expressing a lack of understanding of what the heading 'Thrive Category' referred to on their Care Plan, and what the implications of this were for them.

Section of the Care Plan referring to needs based grouping

Treatment/Care Plan	
PLEASE NOTE: THE INFORMATION IN THIS SECTION WILL BE SHARED WITH THE PATIENT / PROFESSIONALS VIA THE PRINTED CAREPLAN	
Is there a Multidisciplinary Care Plan already in place?	- Please Select -
Current concerns or problems (bullet points)	
Goals /Aims (these don't need to be identical to the Goal Based Measure)	
State briefly treatment to be offered at Tavistock and Portman and by other agencies where necessary?	
Thrive Category*	- Please Select - i
Were iThrive Grids used to support shared decision making?*	Getting Advice Getting Help Getting More Help Getting Risk Support Patient not seen
Discussion of intervention (did you discuss risks, benefits or alternatives?)	
Comments from young person (were there areas of agreement or disagreement / concerns with the Care Plan?)	
Comments from parent	
Proposed Duration of Care Plan	
Review Date of Care Plan (no longer than 6 months)	

This posed a number of challenges, as we realised that the description 'Thrive Category' firstly didn't support the common language, and that it was also not an accurate nor adequate description of the needs based groupings. Consequently, a CareNotes system change request has been submitted to change 'Thrive Category' to 'THRIVE Framework needs based grouping' so that it aligns with information that will be shared with children, young people and their families. Moreover, it was clear that all children, young people and their families could benefit from receiving more information about what the needs based groupings meant for them, and thus a document which could be explored on their own or with a practitioner may help to bridge this gap.



As a result of this, The National i-THRIVE Programme Team supported the development of information leaflets to support understanding of what the five needs based groupings mean.

Who is the intended audience?

The leaflets are intended for all children, young people and families who are engaging in care from the T&PFT, and it felt important for the information to be accessible for the range of abilities who might be accessing them. Thus, following some initial feedback, a decision was made to develop two versions of the leaflet; one of young adults and parents/carers and an easy-read version for younger children or those with additional learning needs. All service users receive paper versions of the Care Plans through the post and/or via email, and ideally both versions of the leaflets would be sent, along with the Care Plans for the families to select the leaflet which they feel is most helpful.

What was the approach to co-developing the leaflets?

We were keen to develop the leaflets in collaboration with service users from the initial design to completion. As we had previously found during the development of the [THRIVE Framework animation](#), remotely delivered workshops were helpful in pooling ideas and gaining feedback despite not being able to meet face-to-face due to the pandemic, and it was felt that this would be the best way to begin our collaboration.

First iteration: first co-production workshop

To enable a spring board to work from, we developed draft leaflets to support discussions with the service user participation group to show what information the leaflets might include and what they might look like. The information on the leaflets briefly described what the needs based groupings mean and went on to individually describe each needs based grouping and their implications regarding help and support in more detail.

1. [View THRIVE Framework needs based grouping explainer leaflets \(parents and carers\), Draft 1](#)
2. [View THRIVE Framework needs based grouping explainer leaflets \(children\), Draft 1](#)

We held a participation group in June 2020 with service users already familiar with the THRIVE Framework through co-developing the THRIVE Framework animation, and asked the following questions to gather a broad range of feedback, as well as giving an opportunity to share general reflections:

- *What are your first impressions? (Likes/dislikes)*
- *Does the wording make sense and is it appropriate?*
- *Would a leaflet like this be useful to you?*
- *What do you think about the look of the leaflets?*
- *What could be improved?*

Example feedback from participation group

"People are really worrying about me". Who are "people"? What if the young person feels isolated and ignored and therefore won't relate to this sentence?

Explain what needs based grouping means.

Thriving:
Thriving means that...

We concurrently asked practitioners from within the T&PFT for their feedback on the leaflets asking the same questions as the participation group.

Example feedback from practitioners

Both documents are colourful, one paged, clear and easy to read, like that it names how: if things are not working – we review it and there is a plan in place to do this.

I like that on one of the leaflets, it details how a young person may not want any support at this time, we have this a lot and it's important to acknowledge the voices and wishes of the young person.

I wonder if the leaflet for younger children was still quite wordy, not sure what the population aim is, primary school?

There isn't a hugely marked difference between the two leaflets.

I like the speech bubbles and what a young person might say.

There was a clear need to create distinct leaflets for younger children or those with additional learning needs, in comparison to older children, young adults and parents/carers. At this stage, it was felt as though we would benefit from the expertise of someone who had created easy-read resources, and thus approached the T&PFT Communications Team, the Team Manager of the Lifespan Team for Autism Spectrum Disorders, and also a contact from our local authority to ensure that the leaflet was genuinely 'easy-read' and accessible.

Example of Additional feedback from clinicians in developing easy-read leaflets

"Increase font to 16pt

Align everything to the left including the diagrams

Use fewer words to capture the meaning of each grouping

Find better symbols for each grouping

Display the diagrams differently so they take up less space – e.g. just use coloured circle sections rather than whole circle

Second iteration

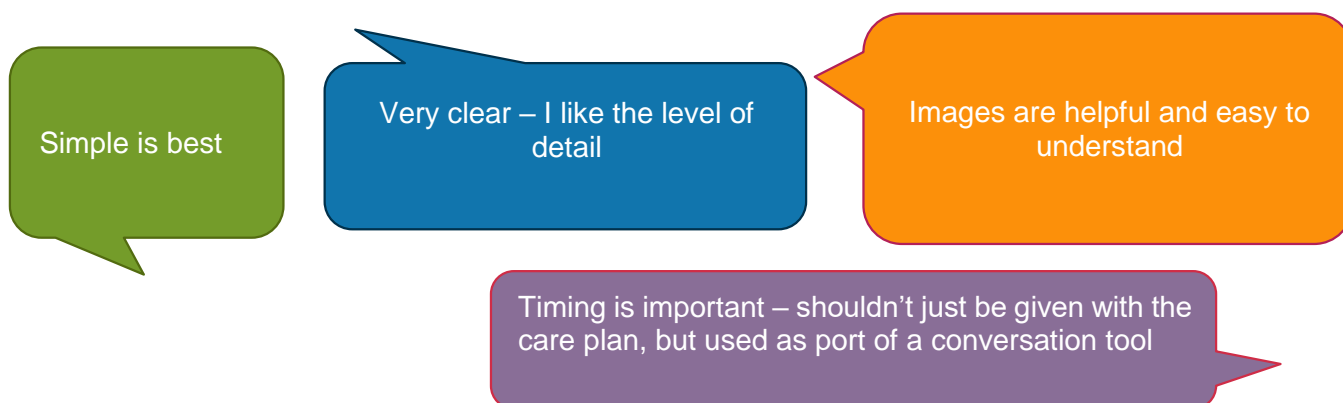
We updated the leaflets to incorporate the feedback we received, and with the support of the T&PFT Communications team further developed the leaflets so that there is an easy read booklet and will be updating the young adult/parent/carer leaflet to include images for each needs based grouping.



1. [View THRIVE Framework needs based grouping explainer leaflets \(parents and carers\), Draft 2](#)
2. [View THRIVE Framework needs based grouping explainer leaflets \(easy-read children/LD\), Draft 2](#)

Final iteration: second co-production workshop

A second participation workshop was held to share the final draft of the leaflets, and they were received positively. Some of the feedback was:



1. [View THRIVE Framework needs based grouping explainer leaflets \(parents and carers\), Final Draft](#)
2. [View THRIVE Framework needs based grouping explainer leaflets \(easy-read children/LD\), Final Draft](#)

How do the leaflets align with the principles of the THRIVE Framework?

The needs based grouping explainer leaflets align with a number of the THRIVE Framework principles:

Shared decision making

The primary aim of creating and disseminating these leaflets is to ensure that service users feel as though decisions about the help and support they have chosen to engage with are made collaboratively. The leaflets were created as a direct response to feedback from service users that the section relating to the THRIVE Framework on their Care Plan was unclear, and have been co-produced with participation groups throughout to ensure the leaflets are genuinely helpful in aiding understanding.

Common language

The leaflets seek to promote a common language by fully explaining what the needs based groupings are, and what each of the groupings mean for the type of help and support accessed. For the older children/young adults/parents/carers leaflet, we were able to reframe the wording available within The THRIVE Framework into 'I statements', to ensure that the phrasing remained relevant and upheld fidelity to the Framework. We also felt it was important to keep the wording of the five needs based groupings the same for the leaflet for younger children and those with additional learning needs, despite feedback that they may be more difficult terms to understand. By maintaining this common language throughout the leaflets and by sense-checking the wording with a participation group, we aimed to socialise service users to some of the words they might come across during their help or support sessions.



Needs led

By creating leaflets to describe the needs based groupings, we aim to reinforce the idea that any help and support offered at the T&PFT has been led according to the needs of the service user at that time. By sending the leaflets with the Care Plans, families hopefully feel as though they have a greater sense about what to expect from the Trust and what everybody's role is in the plan moving forward.

Accessibility

The leaflets were created with increasing accessibility in mind, by ensuring that the language within them was jargon-free and easy to understand, with service user input at every stage. Efforts were made to ensure that all images represented the diverse populations that the T&PFT work with, and moreover the plan moving forward is that everyone can access the leaflets themselves, by receiving them via email and also by post to try to suit the varied needs of our population served. Furthermore it was important that the leaflets were genuinely easy-read and adhered to the evidence-based guidance in creating easy read content. We also aim to translate the leaflets to reflect the many languages spoken by the families accessing our service. This will increase access in response to feedback from our service users and who are open to revising the leaflets further.

What are the next steps?

As an originator site, The Tavistock and Portman NHS Foundation Trust have been implementing the THRIVE Framework since 2014, and the implementation of the leaflets was a positive next step for the continuation of this roll-out. The aim is to pilot the leaflets in a small number of teams at the T&PFT, and audit their use using Quality Improvement methodology; ascertaining a baseline of understanding of the needs based groupings amongst all service users in general and then assessing how often the leaflets are used at home or in a session with a clinician, and also how helpful they are in developing a common language and shared understanding. From here, the intention is to adapt the leaflets further according to feedback; and also to translate the leaflets as necessary to meet the needs of a wider demographic of service users.

These leaflets are available for the National i-THRIVE Community of Practice to make use of pending amendments, and we would warmly appreciate feedback on any amendments which may better suit the needs of a broader audience.

Acknowledgements

Special thanks to the Young Champions, Rufus Carroll, Tomaz, Lie Walters and Gail Walters, Emma-Kate Kennedy and Glenn Gosling at The Tavistock and Portman NHS Foundation Trust and to Polly Lee at Camden Local Authority.

If you would like further information, please contact the National i-THRIVE Programme Team at ithriveinfo@tavi-port.nhs.uk.

Edited by the National i-THRIVE Programme Team.