Presenting information to those on the DSR (Dynamic Support Register)

PaCC Focus Group Report – December 2022

This report is from the PaCC focus group on the DSR, which took place on Thursday 15th December at Community Base, Queens Rd.

BACKGROUND

NHS Sussex is creating a landing page and an information leaflet on the Dynamic Support Register (DSR). The DSR is designed to improve the way children with learning disabilities, autism or both, are supported where they also have behaviour that challenges. PaCC delivered a focus group to gather parent carer views to contribute to this project.

AIM

The aim of the focus group was to look at how information is presented to parents with children on the DSR and gather the views of parents who have accessed the service and from those who haven't but want to know more about it. Specifically, we wanted to hear parent carer views on what should be included and how best to present the information, to help parent carers understand what being on the DSR means for them and their child.

METHOD

The focus group was facilitated by Becky Robinson, PaCC Chair, and by Paolo Boldrini, PaCC Engagement Coordinator.

The focus group was promoted to PaCC members via email. We needed a mixture of parent carers who had some understanding of the DSR and parent carers with no previous experience, so some participants were selected on this basis. 9 parent carers who were from different age groups and whose children have different disabilities and/or additional needs, attended the focus group.

The focus group looked at two main areas:

1) What information about the DSR needs to be available for parent carers?
2) Looking at the 3 examples provided (2 websites and 1 flyer), what is helpful? What shouldn't be included? Is the language ok? Is any information missing? And how should it be set out?

The focus group were given a brief introduction about the DSR;

The DSR is for children and young people (CYP) who have been diagnosed with a Learning Disability or Autism, or both. DSR is connected to early intervention and sets up a care network so that CYP receive the right support at the right time/when needed, with the aim to prevent crisis and hospital admission. Issues that will be taken into consideration for a CYP to be supported through the DSR are failing at school and behaviour that challenges, including CYP's anxiety or unstable mental health. A combination of those will trigger the DSR.

The DSR is managed by the local Clinical Commissioning Group (CCG) and chaired by a commissioner who's responsible for taking notes at the meetings which feed into the CYP's care plan that gets updated continuously. The system offers a support network of meetings which are attended by representatives from various agencies.

CETR and DSR is managed by the Clinical Commissioning Group (CCG) who organize support for those children who have mental health needs and LD and are not eligible for a social worker.

Should a CYP be at risk of hospital admission, a keyworker, the family advocate, will work alongside all the agencies involved, to prevent that from happening. The keyworker is fully involved with the Community Education and Treatment Review (CETR). The CETR focuses on CYP who have been or maybe be about to be admitted to a hospital. The system is very similar to DSR as it brings together services commissioners and providers, nurse, social worker, education and so on ..., including CYP and parent carer/s.

Question 1: Following the focus group introduction about the DSR, what do you think are the key information or areas that need to be available to parent carers when learning about or understanding the Dynamic Support Register?

PARTICIPANTS FEEDBACK

- What support can it offer for family and young person?
- Who refers to a DSR?
- How to get on it, what the criteria is
- Who's responsibility is it?
- Clarify the role of social workers in this
- How does it fit with an EHCP?
- More clarity about the 2 parts to DSR
- Where to find out more
- Clear pathway via a diagram
- Clear 'Search' link and easy to navigate

- Easy to understand so not to be overwhelming
- Enough information to fill the huge gap in knowledge

<u>The focus group were shown two websites and given one flyer, all of which were providing information about the DSR.</u>

Question 2: Looking at the examples, what would be helpful to be included in Brighton and Hove's DSR parent carer information? What shouldn't be included? Is the language used ok? Could it sound scary for parent carers?
And
What information is missing from the examples, and in what order do you think the information should be set out?

a. Flyer from Oxford Health NHS Foundation Trust - see copy below or go to OH-215.20-DSR.pdf (oxfordhealth.nhs.uk)

NHS Oxford Health NHS Foundation Trust

CAMHS

The Dynamic Support Register (DSR) and Keyworker Service for Children and Young People in Oxfordshire

For parents and carers

Concerns and complaints

What is the DSR?

What sort of information is held on the register?

What do we do with this information?

How do we do this?

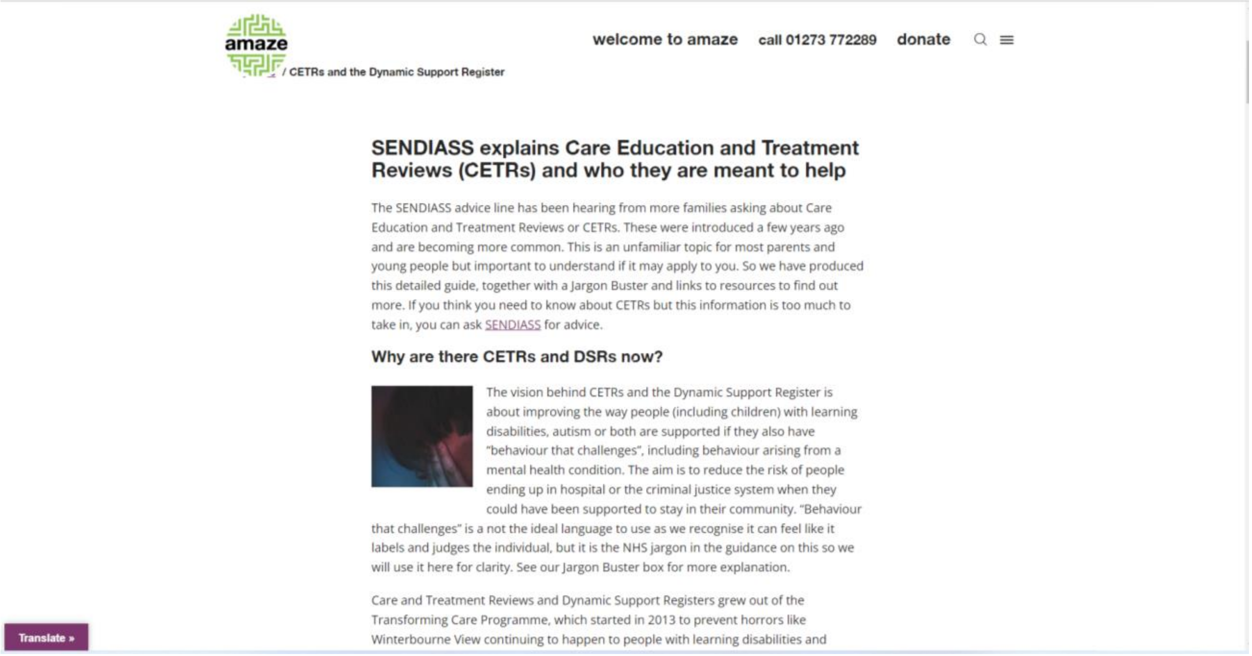
What is a CETR and who might need it?

PARTICIPANTS FEEDBACK

- **Lack of detailed information -** if you don't already have experience of DSR, the flyer isn't helpful. It doesn't say who decides who goes on the DSR, who can refer (omits that you can self-refer), the eligibility criteria or what the journey is. It doesn't say what the service entails including how long the child can stay in the service, or what ages this covers. Does a young person who has accessed the service, stay on the register for life? What is the exit criteria and are there outcomes? What happens if the young person needs the support again? It also doesn't clarify the pathway to support or have enough information about the register, or state whether the same process works for different areas.
- **Too much text -** puts people off reading it, needs to be in an 'easy read' format.

- **Needs more reassurance**; it's not clear that child is central and it's not LA specific and if the child moves, it moves with the child. It does nothing to address the shame and anxiety and calm the parent and also empower the parent. 'Register' is a scary word, as a parent do I want my child on this register? A parent will definitely feel the child has been labelled, so what is the future impact of a child being on the register on things like employment? And how will this data be used? A 'Myth Busting' section could be useful for this.
- **Are 2 different flyers needed? –** one for those who are autistic and one for those with a learning disability.

a) Amaze website page on Care Education and Treatment Reviews (CETRs) and DSR – see copy below or go to https://amazesussex.org.uk/cetrs-and-the-dynamic-support-register/



SENDIASS explains Care Education and Treatment Reviews (CETRs) and who they are meant to help

The SENDIASS advice line has been hearing from more families asking about Care Education and Treatment Reviews or CETRs. These were introduced a few years ago and are becoming more common. This is an unfamiliar topic for most parents and young people but important to understand if it may apply to you. So we have produced this detailed guide, together with a Jargon Buster and links to resources to find out more. If you think you need to know about CETRs but this information is too much to take in, you can ask SENDIASS for advice.

Why are there CETRs and DSRs now?

The vision behind CETRs and the Dynamic Support Register is about improving the way people (including children) with learning disabilities, autism or both are supported if they also have "behaviour that challenges", including behaviour arising from a mental health condition. The aim is to reduce the risk of people ending up in hospital or the criminal justice system when they could have been supported to stay in their community. "Behaviour that challenges" is a not the ideal language to use as we recognise it can feel like it labels and judges the individual, but it is the NHS jargon in the guidance on this so we will use it here for clarity. See our Jargon Buster box for more explanation.

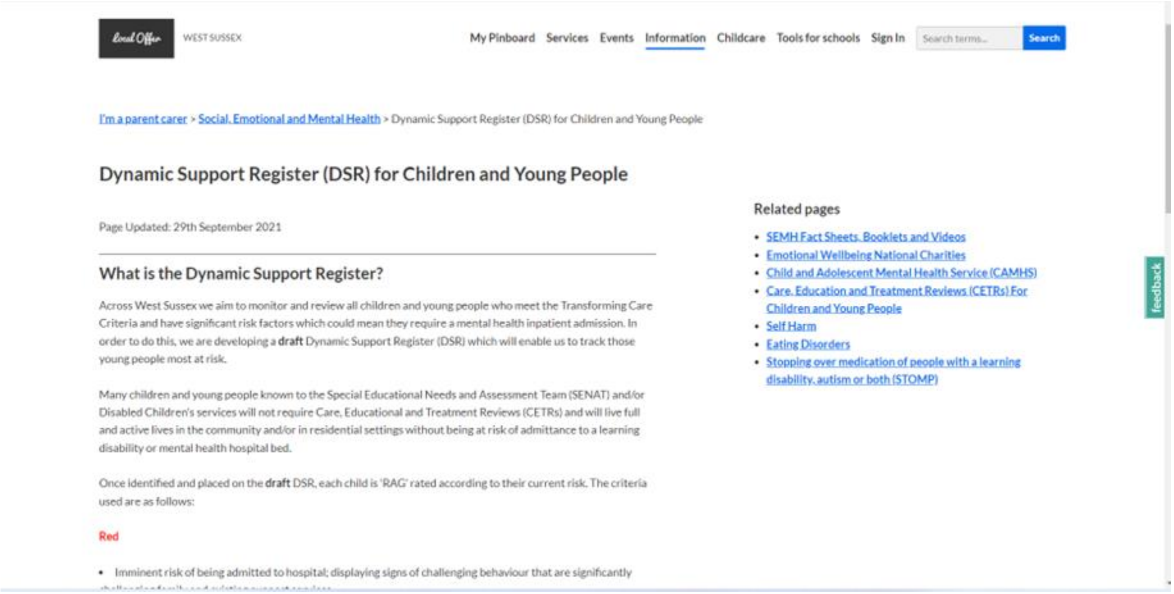
Care and Treatment Reviews and Dynamic Support Registers grew out of the Transforming Care Programme, which started in 2013 to prevent horrors like Winterbourne View continuing to happen to people with learning disabilities and

PARTICIPANTS FEEDBACK

- **Lack of clarification** – no need to mention the Care and Treatment Reviews unless you are going to explain what they are. It also needs to be clear the DSR is early intervention. What happens to those over the age of 18? State whether parents need to agree for child to be accepted onto DSR.
- **Needs more information** – 'Who is this about' is a very good section; on 'for example in an assessment and treatment unit or ATU' but requires a link for more information and explanations; also would be good to have a link to developments on Community Care. The page needs more info on the DSR as it seems overly focused on the CETR. The DSR meeting lasts for 1-1.5hrs and there is time for questions, this should be stated.

- **Information specifically on accountability needed** – What is the role of the NHS? Who is accountable? Parents need to know. What is the process and who do you go to if the system doesn't work? Is there a statutory obligation for services to provide what's been suggested? Or is it only advisory, again needs to clarify where the responsibility lies.
- **Needs more reassurance** – the part about Winterbourne View could be scary for parents.
- **Too wordy** - can it be shortened or use bullet points? And perhaps have links for those people who want to find out more.
- **Location of information** – Put the information about the DSR and the CETR on the Local Offer website.
- **Make important parts bold font** – e.g 'Health, education and social care staff can do this, but parents can too, and young people themselves,...' - **parents can too** needs to be in bold.

b) West Sussex Local Offer page on DSR – see copy below or go to [Dynamic Support Register (DSR) for Children and Young People (local-offer.org)]



I'm a parent carer > Social, Emotional and Mental Health > Dynamic Support Register (DSR) for Children and Young People

Dynamic Support Register (DSR) for Children and Young People

Page Updated: 29th September 2021

What is the Dynamic Support Register?

Across West Sussex we aim to monitor and review all children and young people who meet the Transforming Care Criteria and have significant risk factors which could mean they require a mental health inpatient admission. In order to do this, we are developing a **draft** Dynamic Support Register (DSR) which will enable us to track those young people most at risk.

Many children and young people known to the Special Educational Needs and Assessment Team (SENAT) and/or Disabled Children's services will not require Care, Educational and Treatment Reviews (CETRs) and will live full and active lives in the community and/or in residential settings without being at risk of admittance to a learning disability or mental health hospital bed.

Once identified and placed on the **draft** DSR, each child is 'RAG' rated according to their current risk. The criteria used are as follows:

Red

- Imminent risk of being admitted to hospital; displaying signs of challenging behaviour that are significantly

Related pages

- SEMH Fact Sheets, Booklets and Videos
- Emotional Wellbeing National Charities
- Child and Adolescent Mental Health Service (CAMHS)
- Care, Education and Treatment Reviews (CETRs) For Children and Young People
- Self Harm
- Eating Disorders
- Stopping over medication of people with a learning disability, autism or both (STOMP)

PARTICIPANTS FEEDBACK

- **More information needed** – particularly on who is accountable, statutory duty? and information / link about Transforming Care Criteria. Explain how being on the DSR helps a child and family from getting into a crisis.
- **Visual information** – showing the process, a flowchart for example.
- **More details needed** – What is the duration a young person can be on the DSR, is it updated annually? What age is support available? Which children is this not suitable for? Also, when it states 'Once identified and placed on the draft DSR...' – how is the child identified? What are the criteria? What about parents who are not in the system? Who is assessing 'lack of capacity'?

- **Acronyms and Abbreviations-** Clarify these, especially when used the first time, e.g RAG. Also colours should be listed the other way around from green to amber to red to demonstrate escalation of need / support.
- **Language** – needs to be informal and accessible. Also, what constitutes 'challenging behaviour' examples would be useful.
- **Location of information** – should be online and on flyers which are distributed to GP surgeries, schools etc. How about a video, perhaps with a parent talking about their experience of accessing the services and their own lived experience of the DSR.
- **Accessibility** – translate the information into other languages for those for whom English isn't their first language.

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RECOMMENDATIONS

- **Include plenty of information and where there is not enough space for this, include links so there is the option for parent carers and young people to find out more.**
- **Details are vital, see participants feedback above as to exactly what details about the DSR parent carers need.**
- **Really important to specify exactly what is meant by terms such as 'lack of capacity' or 'challenging behaviour' examples are useful to achieve understanding.**
- **Visual information of the steps of the process to getting on the DSR would be beneficial, e.g a flowchart.**
- **Layout needs to make sense by showing the least severe first to show the escalation of support.**
- **Should be a real effort to reassure parent carers and young people and avoid scary references.**
- **Detailed information about accountability and responsibility of care is particularly needed.**
- **Language needs to be accessible for all; informal language, easy to read with not too many words & appropriate spacing with important parts in bold. Explain acronyms. Translate into other languages for ESL clients.**
- **Needs to be available in a variety of formats and in a variety of places.**

ADDITIONAL POINTS

- It would be good if Jane Taylor could meet with parents, perhaps sometime in March?
- More work needs to be done to capture parent's view. Perhaps to have focus groups/sessions like this one at East and West Hubs and at mainstream schools too.
- Parents need to be included when assessing 'lack of capacity'.

- How can we involve young people on this process? Perhaps one to one, not a group, and parent could interview the young person?
- How do we capture voices of LD children who have severe issues with communication? How a child will understand what has been said or access these meetings? A child who doesn't understand his behaviour is a problem. What would happen to a YP who cannot digest all the information? It would be good to have an advocate for the young person.
- What's the legal aspect when a child is over 18 years old? How does it work? What if the situation goes down the legal route? Can the parent represent the child? The child needs to give consent.
- A focus group to capture over 18 years old voices would be beneficial.
- Perhaps to have an advocate to support the family to attend the meeting? And case worker too if the YP lives in a sheltered accommodation.