



SAR Summer

How to use this document



The aim of this document is to outline the key themes and learning from SAR Summer. Please share this resource widely. It can be used in conjunction with the [https://safeguardingpartnership.swindon.gov.uk/downloads/file/1213/ssp_action_plan_p
roforma](https://safeguardingpartnership.swindon.gov.uk/downloads/file/1213/ssp_action_plan_p
roforma)

There are also hyperlinks to external resources such as websites, which can be accessed by either ctrl+click on the image/icon or hyperlink. Alternatively you can use your mouse to right click and select open link from the options. If you are unable to open a hyperlink please copy the information and paste into your usual internet search engine e.g. Google or Bing.



- Summer was 19 years and 9 months when she died, she had complex medical needs and neurodiverse conditions influencing how she and her parents worked with professionals.
- She had a longstanding Crohn's condition, a diagnosis of Autism and a learning disability. Concerns hinged on her choice of treatment for her Crohn's disease (Holistic - obtained from the United States of America) the influence of her parents on these decisions from childhood into adulthood and the lack of any treatment for Crohn's as an adult despite the risk of harm and death from no treatment. There was a lack of any repeated Mental Capacity Act (MCA) assessments as an adult on this treatment decision (Capacity for this was last assessed at 16 years) and lack of any health follow up.

SAR Summer



Education & Health Care Plans (EHCPs)

The review highlighted the importance of their being systems in place to track and review Education & Health Care Plans for children who are on roll at school but not attending education. It also highlighted the importance of the transfer of plans and information between education settings especially when young people are transitioning to a college setting.

<https://localoffer.swindon.gov.uk/content/send-local-offer/landing-pages/education-health-and-care-plans/menu-education-health-and-care-plan/>

Voice of Summer

It also highlighted that professionals did not always see Summer in her own right especially within health services where the majority of the communication about Summer was through her parents. This raised questions regarding the need to make reasonable adjustments for individuals with learning disabilities and other complexities to ensure they are considered as a patient in their own right.

<https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

Contrary to this, Summer's education provider who worked mostly with Summer on her own, were able to ascertain her wishes, her feelings and respond directly to them along with suggesting/agreeing adjustments to accommodate her needs both physical and how they would work with her educationally.

Autism and Physical Health

The review highlighted that the link between Autism and physical health conditions was not recognised or fully considered by those involved with Summer.

Autism is commonly associated with a range of physical and mental health conditions which appear with greater frequency compared with non-autistic populations resulting in higher morbidity and premature mortality. This is often due to people with Autism reporting that they feel anxious about attending healthcare settings and there is a tendency to avoid this.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

<https://assets.publishing.service.gov.uk/media/60d2e20fe90e0743a210e00f/national-strategy-for-autistic-children-young-people-and-adults-easy-read.pdf>

<https://www.autismspeaks.org/medical-conditions-associated-autism>

Mental Capacity Act

The review found that there were contested opinions on mental capacity assessments which should have been raised through the appropriate channels to resolve the differences of opinion in the best interest of Summer.

[Mental capacity act 16 to 17 year olds learning from reviews](#)

From the age of 16 to Summer's death at age 19, there was only one Mental Capacity Assessment completed; this was completed at the age of 17. After this initial assessment, further Mental Capacity assessments were not completed, because professionals assumed Summer to have the mental capacity to make decisions around declining serious medical or life sustaining treatment.

Professional curiosity should have been applied given that Summer was refusing potentially life sustaining treatment.

https://safeguardingpartnership.swindon.gov.uk/downloads/download/83/resource_pack_-_professional_curiosity



Mental Capacity Act



The Mental Capacity Act 2005 (MCA) is designed to protect and empower individuals aged 16 and over and help to safeguard the human rights of people who lack (or may lack) mental capacity to make decisions about their care and treatment. These include decisions about whether or not to consent to care or treatment. This may be because of a lifelong learning disability or a more recent short-term impairment, for example due to drug or alcohol abuse and mental ill health or long-term impairment resulting from injury or illness.

Principle 5
Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms possible, while still providing the required treatment and care.

However, just because a person has one of these conditions it does not necessarily mean they lack the capacity to make a specific decision. Someone can lack capacity to make some decisions (for example, to decide on complex financial issues) but still have the capacity to make other decisions (for example, to decide what items to buy at the local shop).

Principle 4
Where someone is judged not to have the capacity to make a specific decision (following a capacity assessment), that decision can be taken for them, but it must be in their best interests.



Principle 1
Everyone has the right to make his or her own decisions. Professionals should always assume an individual has the capacity to make a decision themselves, unless it is proved otherwise through a capacity assessment. In emergency situations, professionals should follow their own organisational guidelines on the MCA and how to apply it in practice, e.g. police officers.

Principle 3
Just because someone makes what those caring for them, or in a position of responsibility for them, consider to be an “unwise” decision, they should not be treated as lacking the capacity to make that decision. Everyone has the right to make their own life choices, where they have the capacity to do so.

Principle 2
Individuals must be given help to make a decision themselves. This might include, for example, providing the person with information in a format that is easier for them to understand.



Resources for Professionals

SSP training page

<https://safeguardingpartnership.swindon.gov.uk/info/8/training>

Adults Safeguarding Policies and Procedures

https://safeguardingpartnership.swindon.gov.uk/downloads/file/976/adult_safeguarding_policy_and_procedures

Deciding If You Need to Raise a Safeguarding Concern

https://safeguardingpartnership.swindon.gov.uk/downloads/file/815/deciding_if_you_need_to_raise_a_safeguarding_concern

Multi-agency Meeting Guidance Working with Adults

https://safeguardingpartnership.swindon.gov.uk/downloads/file/1154/multi_agency_meeting_guidance_working_with_adults

Resources for Professionals

Mental Capacity Act for 16-17 year olds.

https://safeguardingpartnership.swindon.gov.uk/downloads/file/1278/mental_capacity_act_16_to_17_year_olds_learning_from_reviews

Guidance aimed at clinicians and social workers on the assessment of capacity.

<https://capacityguide.org.uk/>

Right Help at the Right Time Children's Threshold Guidance

https://safeguardingpartnership.swindon.gov.uk/downloads/download/37/the_right_help_at_right_time_threshold_guidance