CHild and Young Person **E**pilepsy **C**oncerns **C**hecklist - **CHECC**

Young person version

HOSPITAL LABEL **(To be affixed by medical secretary prior to sending)**

Name of individual completing form:	
Any other support helping with this form	Parent / Carer / Other: ……..
Date completed:	

Children and young people with epilepsy have an increased risk of difficulties with physical skills, learning, behaviour, mental health and/or development.

This checklist is intended to help us check for these kinds of difficulties, and to make referrals as needed

Please do look through the form carefully.

Leave blank any sections that you feel you cannot answer and feel free to add comments reflecting your concerns.

Please return this form to the epilepsy team treating you and discuss any queries with them.

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Have you ever wondered if you had	**Yes**	**No**
Autism Spectrum Disorder (ASD) including Asperger's Syndrome		
Attention Deficit Hyperactivity Disorder (ADHD)		
Anxiety, *including as panic, phobia, separation anxiety disorder*		
Depression		
Non-epileptic attacks/seizures		
Other (please specify):		

	Yes	**No**	
If YES to any of the above have you had further evaluation* or support for this?			
Would you like to have further evaluation* or support for it?			
Further comments			

**here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

Are there any other behaviour or emotional difficulties causing concern to you or to other people? Please specify:

Have you ever, or felt you have ever struggled with	**Yes**	**No**	**Comment**
Communication and social interaction concerns			
Difficulties getting on with other people of similar age			
Being rigid about how to do things or not liking change			
Unusual responses to light, sounds, smells, tastes, textures – e.g. seams on clothes, haircuts, nails, washing or tooth brushing routines			

Have you ever, or felt you have ever struggled with	**Yes**	**No**	**Comment**
Over activity/hyperactivity, *such as being constantly on the go*			
Difficulty paying attention or concentrating			
Restlessness or fidgetiness, *such as wriggling or squirming*			
Forgetting items or instructions			

Impulsivity, *such as butting in, not waiting turn*			

Are you concerned about the following	**Yes**	**No**
Swallowing or chewing *such as drooling, choking or spluttering on food or drink*		
Eating too much, too little		
Limited range of foods such as tastes, textures, brands		
Eating unusual things		

Do you currently or regularly have any gut issues such as	**Yes currently**	**Yes regularly**	**No**
Constipation – "hard poos"			
Abdominal (tummy) pain			
Feeling sick or vomiting			

Do you currently or regularly have any sleep issues such as	**Yes currently**	**Yes regularly**	**No**
Difficulty falling asleep			
Frequent waking in the night			
Difficulty waking in the morning			
Other (please specify):			

Do you have difficulties in school or college with	**Yes often**	**No**	**Sometimes**
Reading			
Writing			
Spelling			
Mathematics			
Break times or mealtimes			
Friendships/play			
School arrival or leaving			
If you answered YES to any of the above;			
Has there been further evaluation* or support for this?			
Would you like to have further* evaluation?			

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Have you ever, or felt you have ever struggled with difficulties in specific cognitive and learning skills, like:	**Yes often**	**No**	**Sometimes**
Memory, *such as remembering things that have happened*			
Attention, *such as concentrating well, not getting distracted*			
Dual-tasking/Multi-tasking, *such as doing 2 tasks at the same time*			
Co-ordination/Visio-spatial tasks, *such as solving puzzles or using building blocks*			
Executive skills, *such as planning, organising, flexible thinking*			
Getting disoriented, *such as not knowing the date or where you are*			
Word finding difficulties			
If you answered YES to any of the above			
Has there been any further evaluation* or support for it?			
Would you like to have further evaluation* or support for these difficulties?			

**here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

Have you ever, or felt you have ever struggled with	**Yes**	**No**
Low self-esteem		
Very high levels of stress in your family, for instance between *siblings*		
Very high levels of stress between *parents* (leave blank if you wish)		
If you answered YES to any of the above		
Have you and/or your family had further evaluation* or support for this?		
Would you like to have further evaluation* or support for it?		

**here we mean that a doctor or specialist has asked you about it to understand the issue better or to look for some treatment*

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Safety	**Yes**	**No**	**Don't know**
Have you got a healthcare plan and emergency medication			
Has your epilepsy affected what you have been allowed to do e.g. sleep overs, school activities, trips			
Do you have any additional safety support e.g. monitors or checks?			

If not covered above, have you any concerns about <u>side effects</u> of your epilepsy treatment	**Yes**	**No**	
Physical health – growth, rashes			
Learning/school			
Mood, Mental health/behaviour			
Focus and mental processing			
Fatigue/energy levels			
Other, including treatment not relating specifically to epilepsy (please specify):			

Transition	**Yes**	**No**	
Do you feel you know enough about your condition and treatment options?			
Are you taking some responsibility for your own care, such as taking your medications, as agreed?			
Are your aware of online resources e.g. Epilepsy action, Young Epilepsy, The Channel, Epilepsy space?			
Are there any lifestyle issues, alcohol, drugs, relationships, that affect your treatment?			
Are there any specific issues you would like to raise e.g driving, employment, contraception, pregnancy?			
Other (please specify):			

Barriers to participation								
Taking together all the difficulties discussed above, how much have these bothered, troubled or distressed you? (Please circle):								
0 (not at all)	1	2	3	4	5	6	7	8 (Extremely)

Taking together all the difficulties discussed above, do you think these have stopped you from doing everything you want to do? f so, how much? (Please circle):								
0 (not at all)	1	2	3	4	5	6	7	8 (Extremely)
Taking together all the difficulties discussed above, do you think these have stopped you joining in with your friends and peers? If so, how much? (Please circle):								
0 (not at all)	1	2	3	4	5	6	7	8 (Extremely)

Goal-setting
Of all the concerns listed above, what are your top priorities to work on next?
1.
2.
3.

As this is a draft tool please comment on whether you found this checklist helpful and how?

If you did not feel it was useful at this moment, when do you feel is the best time to complete this?

Was this about right or too short or too lengthy to complete?

When do you think this questionnaire would be useful? For example, before the clinic appointment, in the waiting room, after meetings with school, concerns in-between appointments.

How would you like to complete this checklist? For example, on paper, using a website link or app?

What are your expectations after completing this?

Do you have any other comments to help us develop this further?

For clinicians/epilepsy team

Do you think you will use this information? How?

Do you think there will be useful outcomes as a result, such as signposting for further assessment or exploration or support of particular difficulties or conditions?

Please return completed form to:

For use by assessor:

Impact/burden on the individual/child/family – circle (map to DDCGAS if you wish)								
O (nil)	1	2	3	4	5	6	7	8 (Extreme)