

National Children and Young People's Diabetes Network National Delivery Plan - Aim 1 Schools and Social Care Subgroup Meeting Minutes 27 June 2022 Via Microsoft Teams



	Aim 1 Core Group Members		Role		Network/Organisation	
S	Martha Ford Adams (- ical Lead	London/SEC	
	Margot Carson (MC) Emma Savage (ES)		Manager		North West	
			Manager		Yorkshire and Humber	
	Jonathan Maiden		Administrator		North West	
	Jonathan Malach		7.011			
	Name	Role		Network/Organisation		
		Network	<			
	Kate Wilson* (KW)	Manager		East of England		
	Janet Soo (JS)	PDSN		North West		
	Yvonne Stone (YS)	PDSN		SEC		
	Joanne Summerton	PDSN		Wessex		
	Ambika Karthikeyan	Consultant		West Midlands		
	Kate Scott (KS)	PDSN		Yorkshire and Humber		
	Dawn Reilly	PDSN		North West		
	Nichola Bridget			NHS Southwark CCG		
	Jane Haest**	PDSN		Lead Nurse		
	Adele Swart	Dietitian	<u>۱</u>	Lead Dietitian		
	Oliver Stone-Lee (OSL)	Parent Rep		Parent Representative		
	Charlotte Austin	Type 1 Lea				
	Rachel Sanderson	Parent r		North East and	North Cumbria	
	Anne-Marie Hannah	PDSN		South West		
	Gemma Bills	PDSN		East Midlands		
Apologie	Name	Role		Network/Orga	nisation	
S	Lesley Drummond**	PDSN		Lead Nurse		
	Sharanjit Cheema	PDSN		London – on maternity leave		
	Matt Williams* (MW)	PDSN		East of England		
	Samantha Costello	Dietitian	<u>ו</u>	North East and North Cumbria		
	Keya Ali (KA)	Consulta		Thames Valley		
Agenda:	Education Health Care Plan Project (EHCP) - Rachael Sanderson (Parent rep, North East and North Cumbria)					
	RS talked through her experience with her son who was diagnosed with					
	was 3. Issues with injections in nursery. Became angry and would run away and became					
	aggressive.					
	Found a page called type 1 rights in school. Safe space for parents and carers. Gave advice on how to get an EHCP. The first half of hours are funded by the school and the second half the LA. Reviewed every year and follows the child if they move.					





Found that the process takes about a year to put in place, and most are initially rejected. About 80% are accepted in the appeals process. The criteria are does the child have special educational needs (SEN). This took lots of work to prove that type 1 was a disability and required SEN. The case was initially rejected. Offered mediation which RA rejected as not worthwhile and submitted the appeal. Following this LA stepped in and offered funding full time 1 to 1. Half funded by healthcare and half by the school. RA rejected this since this would not have moved with her child if they were to move for example. The report from the appeal came back that he must be assessed. Now doing very well in school following EHCP being put in place. As part of RA parent rep role, she had put her name out for parents to contact her who were having the same issues. Had many parents contact her so decided to start a project to get the information out there. Developing a flow chart that will take you through the different stages, giving you examples of evidence and guide you through each process. The idea is it will contain pop up videos guides. Worded with SENDIASS to ensure all legalities are all right and the project is time proof and relevant depending on where in the UK you are. Hoping to have the website up and running by the end of the 2022. The information will be hosted on the DigiBete website. Questions around family expenses during appeals etc. RA stated that can all be done by the family if all the information is at hand. BN – SEND reforms and Children and families act 2014, currently a green paper and consultation out looking at changes. Discussion around expectations of legal standards and competencies of schools and school staff with regards to children with long term conditions – Charlotte Austin (CA) CA – DUK working with RS on the above project to support the underpinning and the policy. Survey held showing 25% of CYP in education setting do not have an IHCP in place. Don't feel like the SEND review Green Paper is addressing the needs of children with medical conditions as much as it needs to, and they focus quite a lot on hospital schools. Workshop with department of education recently with aim of alliance members getting this to the DOE, SEND and alternative provision teams that there are so many CYP living with medical conditions in mainstream schooling. Think the next step is white paper which will be a recommendation of what the policy will look like. Study done last year showed only 29% of schools had medical conditions policies. Raised with DoE who were keen to help. Our ask for them is that this is pushed forward in terms of our Ofsted reviewing that schools have medical conditions policies in place and acted on. Similar done in Wales last year on alternative learning needs bill. Spoke about scenarios

where type 1 can lead to educational needs which was fully taken on board. Education and data workshops held with 13–24-year-olds, based on Rob French's research around educational attainment and type 1 diabetes. Basically, there isn't a



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	difference in educational attainment on in robs research, despite children with Type 1				
	having a lot more absences, the attainment is pretty much level, which with children w				
	't have diabetes.				
	Concerning that it looks like that in a graph but there's big parts of this that are missing				
	and that's what we need to put across to people like DoE. Questions around the 25% not having an IHCP in place. CA stated the survey was for parents so wondered whether communication and the family unaware of the IHCP.				
	Questions around school staff competencies and how we take that forward. KS – Has				
	looked into this and not really found anyone who can answer this question. Stated that				
	in Yorkshire & Humber they are looking to standardise their school teaching and				
	competencies and have an online portal where people can go back to.				
	Mobile phone use for diabetes management in schools:				
	JS – Write in IHCP when a CYP is required to use phones in school for diabetes care.				
	Highlighted those consequences where CYP may abuse this privilege.				
	RS – Previous discussion around whether hospitals can provide devices for low-income				
	families. The responsibility could potentially lie with the trust to restrict the devices uses				
	in terms of safeguarding.				
	KA – Could we have a national document, similar to the SW network document,				
	endorsed by the network around using phones in schools to manage medical needs				
	MFA – Maybe use DLA to get phones				
	KW – Unit in East of England managed to get some charity funded devices				
	AOB				
	• AS - Discussion around carb counting school meals. AS has tried to liaise with				
	companies providing food in her area and face difficulties and asked whether any				
	work being done on this. CA stated work being done in Wales and could link these				
	teams with AS. AS asked whether these teams could speak on this group to tell us				
	what work they have done.				
	 Can we add carb counting to the competencies? 				
Actions	*				
Date and	Time: 1000-1130 hours				
time of	Date: Wednesday 5 th October 2022				
next	Venue: Virtually - via MSTeams				
Meeting	Minutes kindly taken by Jonathan Maiden				
	Only one representative from each Network/organisation				
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