

# MENTORING AND ACTIVITIES FOR 2019/20



# CONTENTS

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## SECTION 1:

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### INTRODUCTION AND SUMMARY PAGE 02

## SECTION 2:

---

### PROJECT DELIVERY PAGES 03-08

## SECTION 3:

---

### FEEDBACK FROM BENEFICIARIES PAGE 09

## SECTION 4:

---

### ACKNOWLEDGEMENTS PAGE 10

# INTRODUCTION AND SUMMARY

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Sickle Cell Disorder (SCD) is the name for a group of inherited blood disorder that affect the shape of red blood cells. It is the most common genetic blood disorder in the UK. Sickle Cell is not contagious, people are born with this condition as it is only inherited from both parents who will pass on the gene. People with Sickle Cell produce unusually shaped red blood cells caused by abnormal haemoglobin.

Thalassaemia is also an inherited blood disorder in which the body makes an abnormal form of haemoglobin. Haemoglobin is the protein molecule in red blood cells that carries oxygen. People with the condition produce either no or too little haemoglobin, which is used by red blood cells to carry oxygen around the body. The disorder results in excessive destruction of red blood cells.

Further information about both conditions are available at:  
<http://oscarbirmingham.org.uk/sickle-cell>

## ABOUT OSCAR BIRMINGHAM LTD

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Organisation for Sickle Cell Relief & Thalassaemia Support (OSCAR) is a voluntary organisation and registered charity (1109849) established primarily to promote greater awareness of Sickle Cell and Thalassaemia disorders and to support individuals affected.

We are the only community based local charity in Birmingham providing support services arising from complex issues for those affected by this genetic blood disorder.

Our approach is based on person centred approach to meet the needs of the community. We treat all accessing our services with respect and dignity, understanding needs based on lifestyle, culture, challenges and preferences while looking at the situation from the point of view of the person living with Sickle Cell Anaemia and/or Thalassaemia.

Our vision is to strive to achieve a climate in which individuals and families with Sickle Cell & Thalassaemia blood disorder receive excellent information, quality care and support.

Our aim is to work in partnership to help improve the quality of health, social and economic well-being for children, young people, families and adults living with Sickle Cell and Thalassaemia in the Birmingham and surrounding areas.

**Thank you to BBC Children in Need for the support. Your grant has really enabled us provide a range of activities and mentoring support services during 2019/20 that has help make a difference in the lives of children, young people and families living with long term chronic Sickle Cell and Thalassaemia.**



# PROJECT DELIVERY

## SOCIAL AND RECREATIONAL ACTIVITIES 2019/20

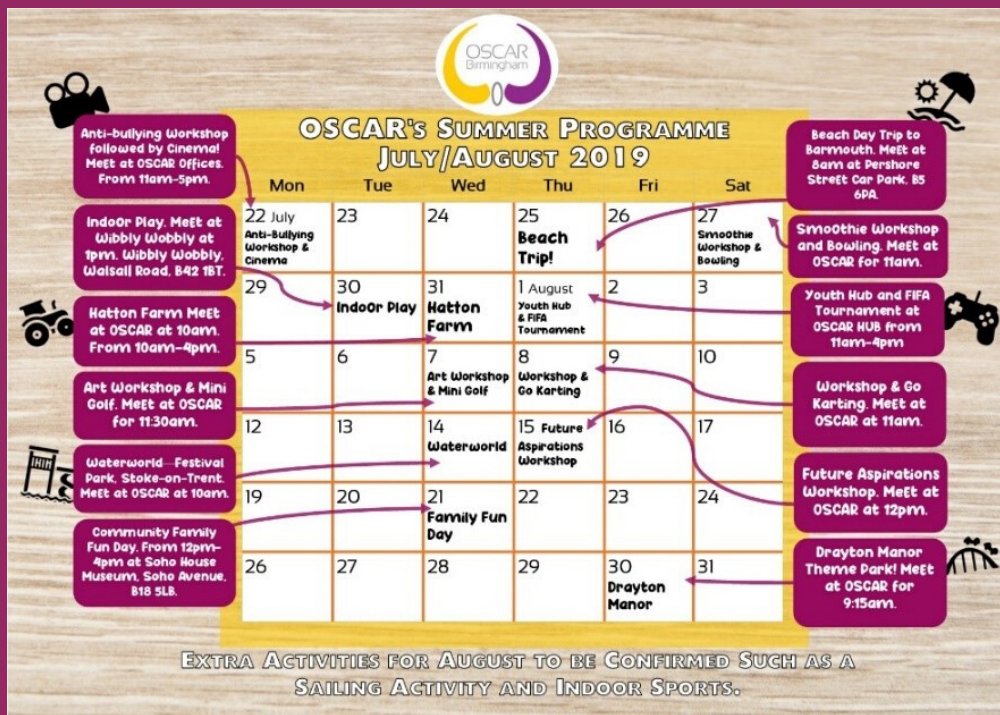
This year has seen our project deliver more activities than in previous years. We have seen an increase in families and children, referred either through existing referral partners or parents self referring. It has been rewarding to be able to provide more activities, bringing and connecting children and families from a range of backgrounds, to make friends and support social, physical and emotional development.

109 children and young people accessed a variety of holiday activities, with more younger children and families being signposted by other families and referred by local children's hospital, particularly for children living with the condition from migrant backgrounds.

Social and recreational activities are enjoyable way for children to keep active, stay well and be happy and support children and young people's healthy development.

Young people who have been engaged in social, leisure and cultural activities are well-placed to apply for training opportunities, employment, and college/university places because they have real-life experiences to talk about. As well as participating in an activity they enjoy, they have also developed important life skills like communicating with others, teamwork, problem-solving and emotional maturity.





**(ACTION-PACKED  
SUMMER  
PROGRAMME 2019  
DESIGNED BY  
YOUNG PEOPLE)**

## FAMILY WELLNESS AND COMMUNITY FUN DAY

Over 240 people attended fun day for children and families at Soho House Museum Handsworth, Birmingham on Wednesday 21st August 2019. This was a community and wellness event, working in partnership with The Active Wellbeing Society, Legacy WM and Birmingham Museums. Children and their parents took part in a variety of fun, active games and access to health and wellbeing information from range of community groups and stall holders.





# MENTORING & WORKSHOPS

Workshops continue to play a vital intervention to engage young people in a range of topical issues that has an impact or of interest to them. Young people took part in range of workshops such as exploring what loneliness means to them and what social connections they have in place or need to create.

Members from our Youth Voice team delivered a presentation on anti-bullying, exploring areas on what is bullying and the harm it causes, the law and how to go about keeping safe.

2 of our mentors ran a workshop on the importance of money management. Topics included income and expenditure, young people attitude to finance, ways to save, information about bank accounts and exploring scenarios.

23 young people had access to mentoring support and/or sessions which resulted in combined total of 403 hours of contact. Mentoring support involved guidance, advice and support for young people to make healthier lifestyle choices, support with education and ongoing interventions with worries and stressors associated with their long-term condition and family situation.



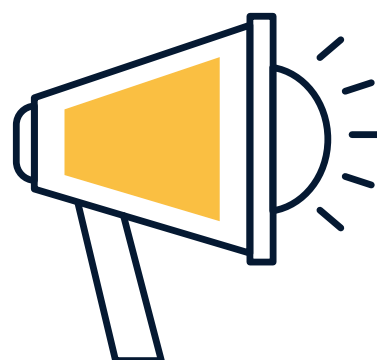


# YOUTH VOICE AND INVOLVEMENT

A place for young people's voices to be heard, to engage with decision makers, to help improve services by co-designing and to connect with others.

At OSCAR Birmingham we believe that young people living with Sickle Cell and Thalassaemia need to be heard, be involved and respected at all different levels on how they review our services, the healthcare system and issues that are important to them.

4 Youth Voice Meetings took place during the past 12 months, with many young people getting involved with a social action project to create a Youth Hub at OSCAR Birmingham during April/May 2019.





# 'GOT IT COVERED'- BBC CIN

Our project had an amazing opportunity to contribute towards 'Got it Covered' a new album developed in collaboration with British Actors as part of Children in Need Appeal 2019.

Between May and July 2019, 21 children and young people took part in either being interviewed, meeting with production team and sharing their stories about living with condition, how the project activities supports and makes a difference to them, with support from Children in Need grant.

This resulted in Adrian Lester OBE, visiting our project and spending the day with children, young people and staff. Getting involved with smoothie and juicing workshop, while joining in and interacting with the group on a bowling activity.

There, Adrian met Aribah, an inspiring young woman living with both Sickle Cell and Thalassaemia disorder. Adrian took time out to listen to her experiences about how an invisible illness has had an impact on her physical and emotional well-being, but more importantly how getting involved with OSCAR has increased her confidence, social participation and meeting others.

Most of the young people taking part, stated being valued, listened to and respected, especially being able to highlight Sickle Cell and Thalassaemia in order to raise awareness and better understanding of this condition to the wider public. It's fantastic that Adrian, is now a patron for OSCAR Birmingham since his involvement with GIC and the project.





# CHILDREN IN NEED APPEAL WEEK 2019

12 YOUNG PEOPLE ALONG  
WITH PROJECT STAFF  
WERE INVITED TO TAKE  
PART IN BBC MIDLANDS  
LIVE APPEAL SHOW AT  
MILLENNIUM POINT. GREAT  
OPPORTUNITY AND  
EXPERIENCE FOR ALL  
INVOLVED!



PROJECT STAFF AND  
VOLUNTEERS  
GETTING READY AND  
IN THE SWING OF  
THINGS DURING  
APPEAL WEEK!

# FEEDBACK FROM BENEFICIARIES

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“

We continuously gather views from children, young people and their families to see what difference the project has made in their lives.

## A PARENT INVOLVED IN THE PROJECT

“

*I really appreciate you all being there for us and helping me with my children.*

*Very inclusive in evolving everyone of all ages and backgrounds. Kind staff- easy to get along with.*

*The activities are extremely fun and enjoyable, and I would recommend OSCAR to everyone and thank you for everything you have done.*

## A FEW MORE QUOTES FROM YOUNG PEOPLE

“

*Coming to OSCAR helps me forget about some of the worries I have.*

“

*I've become more confident and open with meeting new people and talking to different people.*

“

*This project has helped me because I am now more confident, and I am open with more people.*

“

*It's helped me to make better decisions.*

## ONE 12 YEAR OLD HIGHLIGHTED

“

*I wasn't sure how long I would be in hospital and it was so good to see you guys visit me especially when I wasn't feeling too well.*

## ANOTHER YOUNG PERSON

“

*It has allowed me to enjoy new experiences and socialise and have fun with people I wouldn't usually talk to.*

“

*It's always good seeing everyone having fun and taking their minds off stress and worries.*

“

*The project has helped me become more confident and make new friends and I always feel at home and welcomed.*

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# ACKNOWLEDGMENT

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**WE WOULD LIKE TO THANK THOSE WHO HAVE SUPPORTED AND WORKED CLOSELY WITH OUR PROJECT BENEFICIARIES AND STAFF OVER THE LAST 12 MONTHS.**

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Adrian Lester OBE.

Isabel Adams, Edel Robinson and Gillian Taylor from Birmingham Children's Hospital Rare Disease Unit.

Suzi Crawford and Judith Woodburn- Birmingham NHS Community Healthcare.

Dawn Carr and all staff at Legacy WM.

Cameron Arthur, Laura Cassidy and all staff at Soho House Museum- Birmingham Museums.

Michelle Ainsworth and Rebecca Henley from Over the Wall Camp.

Olivia Luder-BBC Children in Need.

James Taylor and Production team at BBC Studios-Got it Covered.

Carla Belle-BBC Children in Need Regional Team.

Tina Price-Publicist

Dee Manning and Active Parks Team from The Active Well Being Society.

OSCAR staff and volunteers involved with this project.

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