

# Lived Experience - 'Down Syndrome'

Sessions- 12.6.23 & 11.7.23. This is a summary of the discussions with parent/carers of CYP with Down Syndrome:

## Areas discussed



Helpful Advice/Support

Services/groups in Bexley

How to share knowledge/  
experience

Missing Advice/Improvements

Top tips/Websites/Good  
Information Sources

## Themes identified



- In general, there seems to be a low expectation of a child or young person with DS from professionals.
- Lack of understanding by professionals of the learning profile of CYP with DS
- Parents have done their own research online
- Lack of information provided at early stages - Early Intervention is needed
- Need for a Down Syndrome group in Bexley as parents are having to go out of the borough
- Parents have found being put in contact with other parents of a child with Down syndrome in the early stages, great support and should be encouraged to be facilitated more
- Support groups are often too general, not taking into account the DS profile
- There is a lack of confidence in the specific knowledge & skills some professionals have in working with CYP with DS.
- Parents are not always aware or given short notice for groups or S&L sessions. No consideration is given to working parents.
- Getting tests and checks for their CYP feels very parent-driven and not always aware of the checks/tests their CYP may need at different times.
- Age thresholds for services do not match the needs of CYP with DS as often transfer to adult services at 18. A need for age to match EHCP support which lasts until 25.
- The Local Offer Website holds lots of information which can be hard to navigate to find information that is relevant. Parents are not always aware of Local Offer or Officer whom they can contact for advice/signposting.
- Help is needed with choosing school settings. Reliance on Facebook groups for information. Would like more honest information from professionals about what is suitable.
- Very little is in place for pre-schools, lack of support and resources.
- Lack of social care involvement. No support/provision given out of term time. Paying 3x amount for 1-1 care in the school holidays.
- Lack of understanding in schools on the resources available that are suitable.

## Follow up



### Actions to be taken:

- Designated Clinical Officer to look into other NHS Trust's Pathways for DS.
- Designated Clinical Officer will look into the number of people with DS in Greenwich
- Designated Clinical Officer will look into out-of-borough support groups and contact them for more information
- Designated Clinical Officer will feedback on issues discussed with relevant health services and seek further feedback from parents as required.
- Designated Clinical Officer will raise issues around community paediatricians with the team at Acorns
- Designated Clinical Officer will give feedback to relevant services regarding short notice of sessions, lack of automatic referrals from an early age and feedback around virtual appointments.
- Bexley Voice will feedback on issues raised about accessing/navigating Local Offer with The Local Offer Officer.
- Lisa Randall, Bexley Voice Chair will raise concerns about social care input and gather information for feedback

### To explore an additional session on:

- Holding a DS conference to share what is on offer and happening in Bexley and for parent/carers to share their views



Link up with other parents & families with a child/young person with DS if possible as a support.

Support Groups - Information available on BV website