Autism and diabetes

What are the issues raised with working with young people with diabetes in clinic settings, and in the service generally, and what adaptations/resources are psychologists using to help support them and their families.

- High proportion of people with Autism in diabetes clinics – is there a higher rate of autism in the diabetes population?
- What's the best way to support people with ASD in diabetes teams?
- ISSUES RAISED?
    - Disproportionate level of people with autism
    - Struggles adapting to change
    - Dealing with tolerance (e.g. physical discomfort, changes of doses, being able to deal with uncertainty)
    - How other members of the team communicate with these young people in a sensitive manner
    - Pattern of micromanagement of diabetes > burnout> disengagement > poor adherence....
    - Wanting to develop teaching/training for colleagues
    - Solution focused model within clinics - how to make abstract concepts accessible to young people with ASCs
    - How to develop flexibility when we set very fixed goals around diabetes care

- Fixed diet, unique management strategies that are developed (which seem to work but freak out the medical team!!!)
- Undiagnosed ASD, family members with ASD
- Hypersensitive to blood glucose changes - behaviour changes (in relation to BG levels) more significant in children with ASD
- Robust enough communication with support system around the young person who may not be able to communicate (e.g. communication with schools about dose changes)
- Transition to high school where there is an expectation for greater independence
- Comorbidities with autism – someone who is either significant impairment or sensory issues
- Sensory issues – coping with sticky-ness of devices
- Annual blood tests and working with other colleagues to support someone with this
- Sensory sensitivities – food texture, ARFID diagnosis and impact on diabetes care

Workshop 1

Autism and diabetes

What are the issues raised with working with young people with diabetes in clinic settings, and in the service generally, and what adaptations/resources are psychologists using to help support them and their families.

Resources/ ideas

- Meta analysis didn't show evidence of higher proportion of people with ASD in the diabetes population
- Visuals – timetables, Now and Next board
- Schools generating resources with the computer packages they have access to
- Individualise approaches
    - Hospital passports
    - Thinking about how to make clinics 'safer'
    - Engineering things so clinics are positive experience
    - Same doctor, same room
    - Giving warning about blood tests in advance – preparation appointments
    - Liaising with schools – EHCPs
    - Social stories for clinics
    - Card to indicate to team that a young person doesn't want to talk anymore in the appointment
    - Board in clinic with the staff who are present in clinic

- Sensory machine – to help with regulation, keeping a young person busy so that the parents can engage with the appointment

ARFID:

- Assessing how much of a problem this is for the family
- Issue when insulin is given and young person can't tolerate the food they have given insulin for – risk of hypo and how this is managed
- Splitting insulin
- Stories that families bring to diagnosis - 'I have diabetes so can't have xxxx' (good vs bad foods)
- Reassurance – bodies can cope with a lot!

- Extended pump trials
- Problem solving, flexibility around their needs
- Sensor data vs capillary test – visual representation or metaphor – train with driver (Blood glucose) and carriages (tissue glucose) to explain discrepancy

Workshop 1

Autism and diabetes

What are the issues raised with working with young people with diabetes in clinic settings, and in the service generally, and what adaptations/resources are psychologists using to help support them and their families.

- Are there more people with ASD in the diabetes population or are we just better at spotting autism?
- ISSUES:
    - Sensory needs particularly around technology
    - Needle and blood test phobias – high resistance to intervention to support this
    - Responsibility – executive function and planning, having the motivation to engage with diabetes care, not thinking about the future, not being as concerned about the social aspects of not looking after diabetes (e.g. parents being upset by their lack of adherence)
    - Coping with the flexibility of diabetes and diabetes burnout
    - Another way of feeling different
    - Not having a good body awareness and not feeling hypos or hypers
    - Rigidity of routine, eating particular foods, issues with rotating injection sites
    - Parent understanding of autism

- Transition and how we can prepare young people for the 'adult diabetes world'
- Helping support a person to cope with change
- Issues around how information is given (verbal information may not be the best format and teams may need to provide written information)
- Creating flexibility in the way the team works with young people with autism
- Link with CAMHS –how to work effectively together
- Waiting times for ASD assessments
- Access to support post a diagnosis of ASD
- Challenges of having 2 diagnosis (e.g. ASD and diabetes) and families not feeling like they fit in either camp

Workshop 2

Autism and diabetes

What are the issues raised with working with young people with diabetes in clinic settings, and in the service generally, and what adaptations/resources are psychologists using to help support them and their families.

Ideas/helpful strategies

- Autism training for the diabetes team
- Lots of repetition even when teaching and training has been done
- Clinic appointments:
    - communication passport – smaller than a hospital passport (2pages) - likes/dislikes, sign of stress, strategies for managing stress, blood test routine (what are their preferences), waiting room, texting a person when the team are ready to see them so they don't have to go to the waiting room, picture of who will be in the room
    - Involving family in communication passport, giving preparation time for young person to complete this.
    - Discussing communication passport in handover meeting before clinic
    - Diabetes team recognising the challenges faced by parents of children with ASC and diabetes

- Pictures of staff on board, and who else is available to be seen
- Peer/parent support group
- Working with school – if someone has an EHCP asking schools to develop some visuals as they may have access to computer packages
- Nurses developing a better understanding of child's level of ability, understanding of maths from school information.
- Training with teams around ASD – understanding the team has of autism
- Social stories – using these for young people and staff around them
- Helping young people to understand the point of the annual blood tests, showing the equipment, visits to the labs
- Videos on digibete to explain all the annual review processes ("why am I seeing a psychologist?" "what happens to my bloods?")

Workshop 2

Children and Young People's National Diabetes Network

Autism and diabetes

What are the issues raised with working with young people with diabetes in clinic settings, and in the service generally, and what adaptations/resources are psychologists using to help support them and their families.

ISSUES FACED BY TEAMS:

- ? Disproportionate number of individuals with ASD and diabetes?
- Struggles around adapting to change (e.g. introduction of technology, changes in insulin doses)
- Sensory issues – coping with things like sensors, pumps, annual blood tests, hypo unawareness
- ARFID
- Teams struggling to communicate effectively
- Use of abstract concepts and how to make these more user friendly
- Working with parents who may also have traits of ASD or a diagnosis of ASD
- Diabetes burnout in young people with ASD
- Transition – how to effectively prepare a young person for life in adult diabetes service where support levels are different

HELPFUL STRATEGIES/APPROACHES

- Hospital passports/communication passports
- Adaptions to clinics
  - young people receiving a text when the team is ready to see them so they don't have to wait in waiting room
  - limiting number of team in room
  - Card for young person to indicate when they don’t want to talk in clinic
  - Visuals of who will be in clinic
- Visual timetables
- NOW and NEXT boards
- Working with schools to understand a young person's needs and asking for support in developing resources
- Social stories
- Using Digibete videos to explain different processes
- Staff training around autism

Summary