

Barnet's Novel Approach to Integrated Care for Children with Down Syndrome

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The Case for Change - Parental feedback for education and health services in Barnet:

"multiple appointments, why do we have to go to hospital even though my child isn't sick, confusing system, disjointed care, feel isolated, don't understand the system, lots of travel across the borough for different appointments"

The BIG DS Hub - The Barnet Integrated Groups for Pre-School Children with Down Syndrome

Held at Underhill Childrens Centre.

- Weekly communication group: pre-school teaching team led. Delivering evidence based early intervention therapy. (DSEi see & learn).
- Initially Community Paediatrics joined the hub-monthly clinics.
- Now also Dental and SLT clinics.



Benefits for the children:

- Brings health care, therapies & education to the community.
- Professionals working around the child rather than the child working around the professionals.
- Limiting appointments in a clinical setting; de-medicalising developmental check ups.
- Regular intervention with evidence based strategies.

Benefits for the family:

- Support for families, increasing confidence and knowledge
- Sense of community
- Non-threatening, non-judgemental, safe environment
- Less time travelling to appointments/term time
- Held in Childrens Centre: access to services e.g. behaviour support, breastfeeding support, playgroups, ESOL classes
- Help on hand with EHCP/DLA/SENIF applications.

Benefits for the professionals:

- Collaborative working within the MDT. Identify problems/find solutions/ facilitate smoother referrals between teams.
- Dual assessments with different specialties e.g. feeding/dental/medical.
- Training opportunities for all MDT trainees.
- Inter-MDT referrals easier.
- TAC meetings easier to arrange/ less intimidating.
- Oromotor subgroup formed to discuss new research across disciplines



Challenges:

- Lack of equipment (e.g. scales)
- Limited access to online results/notes
- Lack of nursing support for observations
- Time management in a non-clinical setting.
- Coordination with other services and their clinical commitments.

The Future:

- Through the LEG and the Combined Care Pathway, communication amongst the MDT has vastly improved. Clear communication of need and a unified approach to care has lead to changes to care delivered e.g. gaps identified in service for feeding assessments now resolved.
- Termly MDT meeting: discuss each child/highlight problems interventions.
 - Commissioning to fund vital equipment e.g. oroscope/SOGS/IT.
 - Young adults with DS joining us for work experience in May.

Leading Edge Group (LEG)

- Multidisciplinary tri-annual meeting: Representatives from education, health, integrated services, parents.
- Responsive to changing needs of the population.
- Ensure Evidence Based practice in all aspects of care around the child.
- Hold a conference for all members of MDT/carers every 2 years.
- Clear communication channel for MDT professionals involved in the child's care.

Child & family



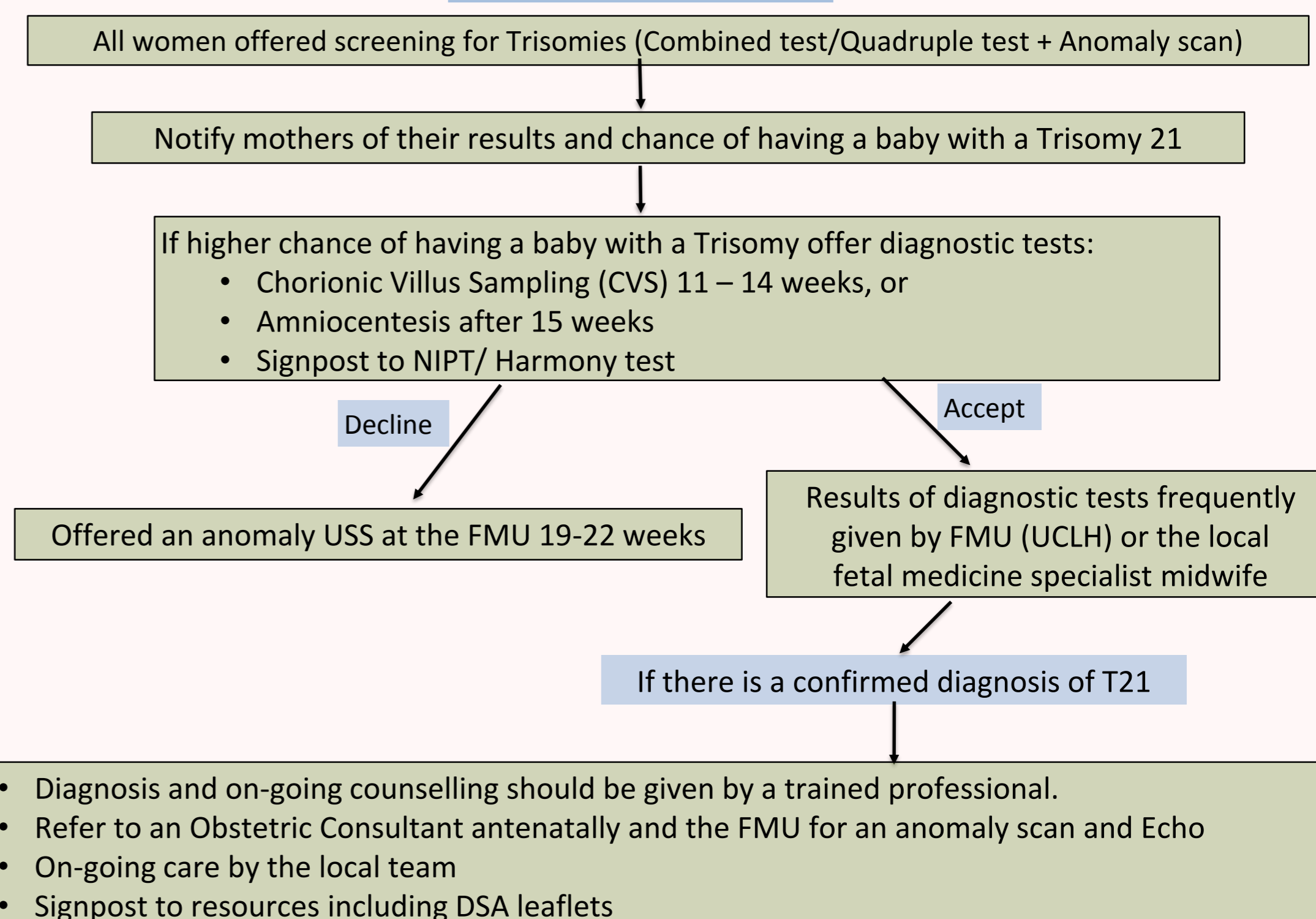
The Combined Care Pathway

A multidisciplinary collaboration between health, education, integrated services, community services and social care to create a streamlined pathway from antenatal diagnosis up until transition into adult services. Key features include:

- Transparent and easy to navigate for professionals and families.
- Checklists for key health checks, referrals, transitions.
- Ensures that evidence based care and best practice is delivered.
- Lead by a subgroup of the LEG.
- Independent to changes in staffing.
- Single point of entry.
- Adaptable to changing needs and auditable.
- Published on the Barnet Local Offer website.

The right people • In the right order • In the right place • Doing the right thing • In the right time • With the right outcomes
All with attention to the patient experience

Antenatal Pathway

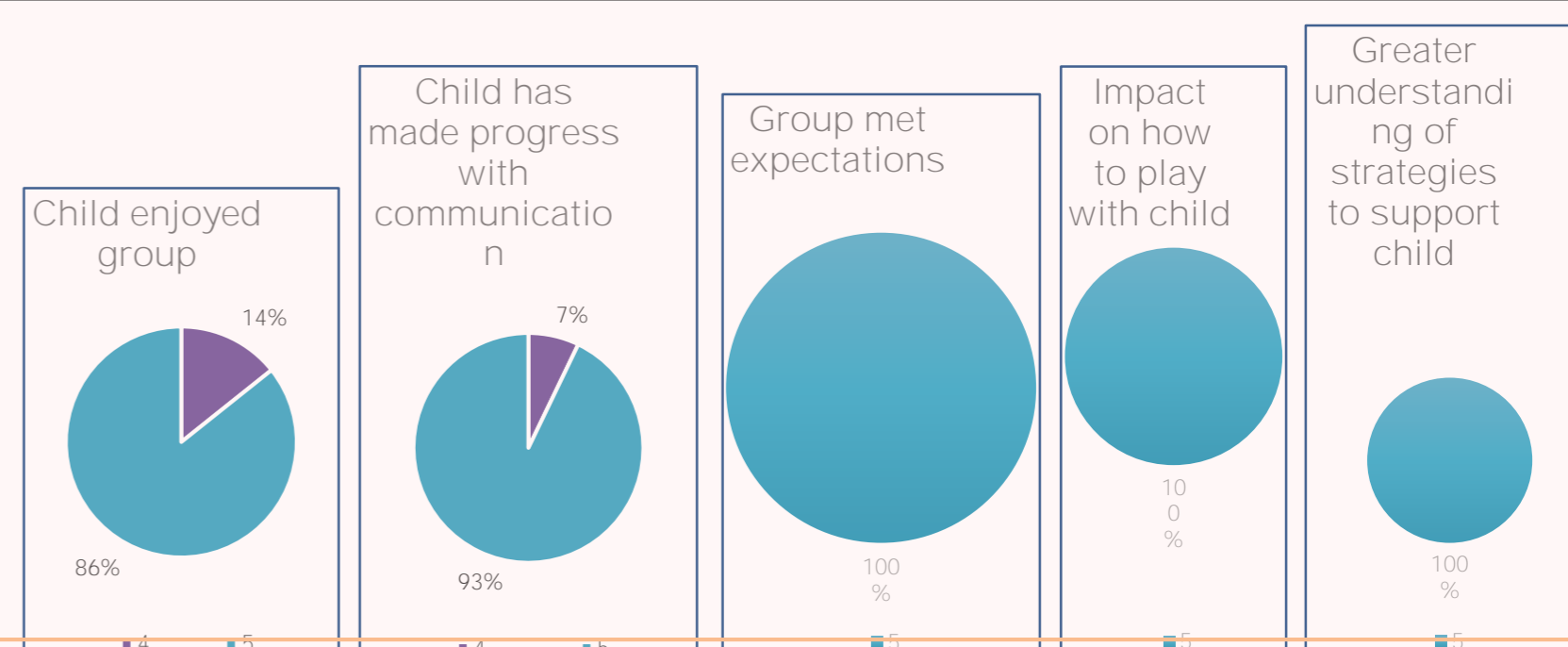


Parental Evaluation of the BIG DS

Results from October 2017 - since then we have started paediatric appointments, feeding clinic and TAC meetings

A few of the comments:

- Can't wish for a better early education teacher! Learnt Makaton
- Better understanding of working with numbers/number concepts
- Systematic use of flashcards to reinforce learning sounds
- **Improved my communication with my child: signs/single works/lining 2 words together**



References/Resources for development of medical pathway and intervention strategies:

- 1) "An evaluation of the early intervention service provided to pre-school children with Down syndrome in Barnet" - Sandra Redman and Sue Bills, Barnet PSST.
 - 2) "Barnet Leading Edge Groups - Special Educational Needs and Disability Support in Barnet" - Sarah Geiger, Down syndrome group lead coordinator and senior Educational Psychologist.
- Resources: DSMIG (Down's Syndrome Medical Interest Group), (DSE) Down's Syndrome International, (DSA) Down's Syndrome Association