
Children with Disabilities Family Support Pathway – Example

1 Introduction

This document provides an example family support pathway for children with disabilities, which can be adapted for local use. A clear and effective family support pathway will facilitate access to and provision of services and support.

This document has been prepared by the [Institute of Public Care \(IPC\)](#), and is taken from our work with local authorities. It is suitable for use in Wales.

2 Who is this family support pathway for?

This family support pathway is for children and young people up to 25 years of age, with physical or learning disabilities.

3 What is a family support pathway?

A family support pathway shows the journey of a child and family over time, from the family's point of view. It is grouped into a series of stages. The pathway tells everyone involved what should be happening, and it can help families and professionals make sense of a complex world.

Each pathway stage in this document describes the following:

- **Event** A period of time or key event in the life of the family.
- **People involved with families** Which professionals should be involved with parents/carers and children and young people. To provide holistic services, multi-agency working will need to be a key part of this process.
- **Where** Where things should happen.
- **When** At what point in time should things happen. For example the length of time to wait for a service.
- **What can we expect?** What should happen, i.e. a list for the family and the professionals to check whether the right things have happened.

Specific child-focused interventions are not described in this paper, but they would need to be evidence based, and acceptable to the child and family.

4 How has this family support pathway been created?

This section describes the information that has been used to inform this pathway.

4.1 National information

Early Support Wales (www.earlysupportwales.org.uk) has been set up by the Welsh Government to improve services for disabled children and children with additional needs and their families. Early Support is the Welsh Assembly Government's recommended approach to achieving co-ordinated, family-focused service delivery for children under five, with known or emerging disabilities. Resources for professionals to use include the *Early Support Multiagency Planning and Improvement Tool*¹, which sets out the following principles of family support:

1. Wherever possible, families are able to live 'ordinary lives'.
2. The uniqueness of children and families is valued and provided for.
3. The care that disabled children receive is based on joint assessment, planning and review processes that keep parents and carers at the heart of discussion and decision-making about their child.
4. Children and families experience service delivery as holistic, co-ordinated and seamless, facilitated by a key worker where appropriate.
5. Families experience continuity of care through different phases of their engagement with services.
6. Children's learning and development is monitored and promoted.
7. Families are able to make informed decisions.
8. Families and children are involved in shaping and developing services.
9. Working practices and systems are integrated.
10. Families can be confident that the people working with them have the training, skills and experience required to meet their child's needs.

This pathway aims to meet these principles for disabled children and young people.

¹ *Early Support Wales Multiagency Planning and Improvement Tool (MAPIT)*, 2009, Welsh Government

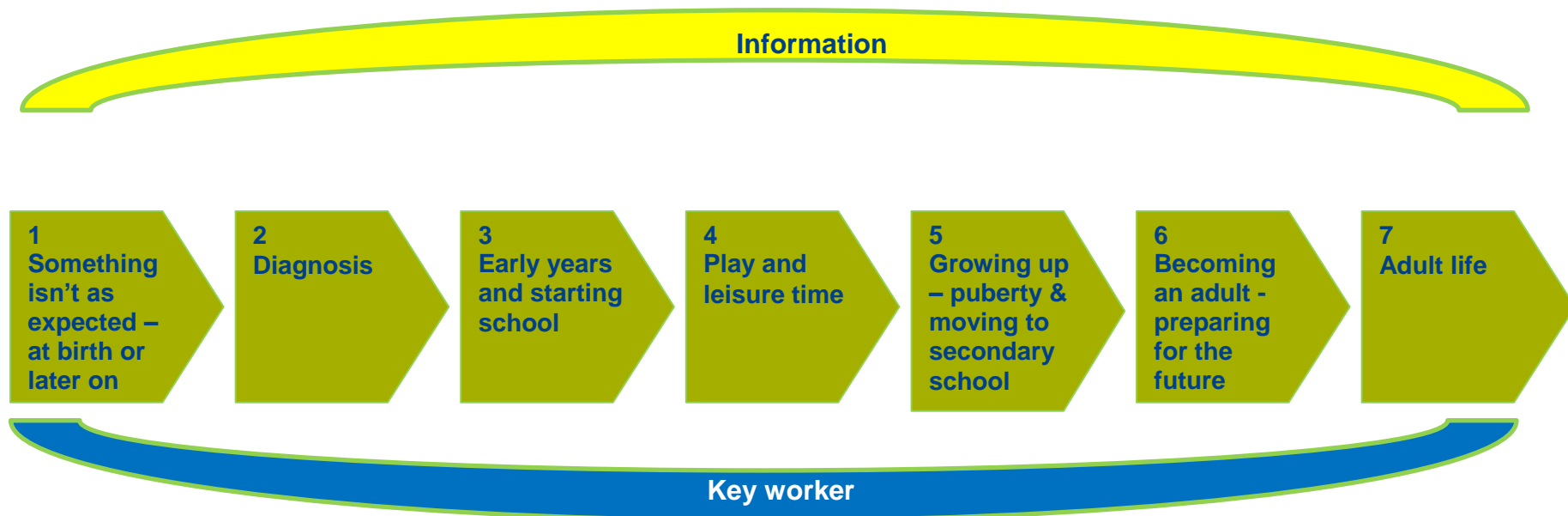
4.2 Local information

This section would need to provide the local context and detail local work that has taken place to inform the pathway. This could include for example:

- Production of a commissioning strategy.
- Interviews and/or surveys with children, young people, parents and carers.
- Workshops with staff and families.

5 Events

This family support pathway is centred around a series of 7 'events' representing key events, or periods of time, for children and young people with disabilities and their families. These events have been drawn from interviews with families, who described significant events or periods of time in the life of their child and cited particular 'pressure points' along the way. These events have also been informed by discussions with local professionals who cited similar events in the lives of children.



Each event is described in detail below.

Information is given to parents along the whole pathway. Details are given in Section 6 Information below.

The **Key worker** is someone who supports parents along the whole pathway. Details are given in Section 7 Key worker below.

1
Something
isn't as
expected –
at birth or
later on

Event 1: Something isn't as expected (at birth or later on)

People involved with families

Parents know their children best and will often be the first to notice that their child may need additional help. The people involved will vary dependent where/when parents notice that something is not what they were expecting. Any of the following could be involved for example:

Family member, Friend, Parent/carer support group, Health visitor, Specialist health visitor, Specialist nurse, GP, Paediatrician, Hospital doctor, Teacher, Independent third sector provider e.g. playgroup leader

Where

For the initial contact, this is dependent on which person or group is involved – see list above. Subsequently, the location of meetings with professionals need to be dependent on the type of needs, and/or convenience for family.

When

When something isn't as expected either at birth, or if later on, as soon as parents make contact with any of the above. Family members, friends or parent/carer support groups may signpost the family to services. At the point in time when the family make contact with a professional, the professional person has a responsibility to help – see below.

What can we expect?

The aim at this stage is to ensure that parents feel supported from the start. Parents should be given clear explanations about what is going to happen next, and where to get further information and help. Professionals should recognise the vulnerability of families where there is a child with disabilities, and be aware that for disability services “one size does not fit all”.

Regardless of which professional person is involved first, parents should be given information, in person, as follows:

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- What will happen next. This to include who will make the diagnosis (if known), where, and an indication of the associated waiting time, and what parents need to do to take this forward.
 - Where to get more information about the disability in the meantime including trusted and reliable websites.
 - The contact details of a professional to speak to. This person will be able to provide information about support – see below.
 - An up to date copy of a booklet, plus the relevant website address, giving information about services.

For those families where disability issues have arisen at birth, or where the issues identified later are severe enough to warrant a diagnosis, a key worker is assigned to the family at this point – the key worker will have been notified via the first professional person involved. Alternatively, the family may choose a key worker who is not a professional. This person will be the main contact between the family and professionals. See section 6 Key worker below.

At this stage the key worker will start to look in detail at the needs of the child/young person and the support needs for the rest of the family and start to record this information all together in one document². If parents prefer, a separate ‘carer’s’ document can be drawn up. This document will include contributions from relevant professionals, for example from health, education and social services. From this document the key worker will work with the family and professionals to draw up a plan which says:

- What the outcomes to be achieved are for the child and the family i.e. what changes do we want services to achieve and by when. There will be an focus on getting services in a timely fashion, including speech and language therapy and specialist intervention for example toileting.
- What services will be provided including times/location/frequency/who/and any waiting times.
- Which equipment and/or adaptations will be provided and by when.
- When the plan will next be reviewed, and who will come to the review meeting and where it will be held.
- Which agencies parents have consented to share their information with including the assessment and plan.

For children with physical disabilities where medical and nursing care has been provided in hospital, a plan for leaving hospital is drawn up by the key worker. The plan will include details of the follow up services to be provided, including which dates/times, where the service is to be delivered and by who and how often. The plan should also say how often the service will be reviewed, when the next review will be due, and who will come to that review. Review meetings take place as set out in the plan.

² Professionals may refer to this document as an ‘assessment’.

At this stage the following information will be given to parents via the key worker:

- What is likely to happen at and after diagnosis.
- The name of someone to contact if the key worker is not available, including an 'out of hours' contact.
- What support is available including short breaks, counselling and support groups (these may be specific to the condition).
- An offer to be put in contact with someone in the area who already has a child with the same or similar condition, to share experiences about what to do and what's available. (Parents who are providing help to others will be given support to do so).
- What support is/could be available to the rest of the family.
- Information about direct payments (and an offer to be put in contact with another family who has already tried this).
- An up to date copy of a booklet, plus the relevant website address, giving information about services.

Parents will be provided with an invitation to be placed on the Children with Disabilities Register, via the key worker. The Register is used to inform planning of services and as a way of keeping in contact with families about events, offers and services.



Event 2: Diagnosis

People involved with families

Consultant doctor, specialist nurse, key worker.

Where

Location dependent on the type of needs, and/or convenience for family, for example at a health centre, children's centre, or in the family home.

When

Diagnosis will be given dependent on the circumstances of the individual child. Services are based on the needs of the child rather than the presence of a specific diagnosis.

What can we expect?

The aim at this stage is to ensure that parents are given clear explanations about their child's disability, know what services are available for their child and understand what support is available to them as parents.

The diagnosis should be given in a face to face meeting with parents, followed up with a confirmation letter. (For any diagnosis that is not given within 3 months of initial contact, a letter is written to parents explaining why diagnosis is delayed and when it will occur.) The meeting should cover the following:

- The disability, and how it will/may change over time.
- If no diagnosis is given, the reasons for this.
- Any further tests that need to happen.
- What medical checks will take place – how often, where and by who.
- Details of the medical or nursing care that will be provided, how often, where and by who.
- Where to get more information about the disability, including reliable and trusted websites.
- Options for counselling for parents.
- What support is available including short breaks, counselling and support groups (these may be specific to the condition).
- An offer to be put in contact with someone in the area who already has a child with the same or similar condition, to share experiences about what to do and what's available. (Parents who are providing help to others will be given support to do so).
- What support is/could be available to the rest of the family.

Parents are given an Early Support Developmental Journal³ to enable parents/carers, family members and the practitioners they work with to notice and celebrate everything that a child learns to do, as time goes by.

3
**Early years
and starting
school**

Event 3: Early years and starting school

People involved with families

Key worker, early years care providers, teachers, additional learning needs staff, nursing, independent third sector provider e.g. playgroup leader, children's centre staff

Where

Location dependent on the type of needs, and/or convenience for family.

³ Developmental Journals for Wales: <http://www.earlysupportwales.org.uk/materials/djs>

When

Before significant events and at least twice a year, dependent on need. Before age 3 if a special school is needed.

What can we expect?

The aim at this stage is to establish early networks and ensure smooth moves into child care and school, and to ensure that families continue to receive support and services early on to help minimise problems from arising in the future, in line with the Special Educational Needs (SEN) code of practice.

The key worker role is significant and will ensure that parents are aware of child care options and early years services, including Portage, and whether they qualify to receive these services.

When new services are started, the parents do not have to retell their journey – the key worker ensures that any new professionals are aware of the child's needs.

Services are focussed on providing early support to prevent bigger problems later e.g. behaviour management, independence training. Parents are trained where necessary for example to provide medical care, to operate equipment, to use behaviour management techniques. Any service has an outcomes focus in other words it's clearly stated where you want to get to, and the service is reviewed periodically to check that outcomes are being met.

Moves such as starting child care/early education services and starting school will be planned by the key worker and the parents together with other relevant professionals such as the play leader or teacher. A plan is drawn up for each move and contains outcomes for the child. The plan also contains practical information such as the transport arrangements for getting to and from school. The plan will be reviewed after the move has taken place.

Meetings are held, and services delivered, in appropriate venues which are convenient for families and where professionals are located. Pre-school this could be at a health centre or children's centre for delivery of health and therapy provision, and later at school for delivery of health and therapy provision for school age children.

Any change in key worker is planned in advance and carefully managed to ensure a smooth handover.



Event 4: Play and leisure time

People involved with families

Key worker, play/sport co-ordinators, national or regional disability sport organisations, club leaders

Where

Local play and sporting venues, children's centres, clubs including after school clubs

When

Throughout childhood and teenage years

What can we expect?

The aim at this stage is to ensure that families know what is available and that children and young people have opportunities to join in play and sport activities, and after school facilities, appropriate to their wishes and needs.

Parents are regularly provided with up to date information about what play and sport opportunities are available – via the key worker, support groups, and also via mailings from the CWD register.

A range of play and sport activities are available on a regular basis. Socialisation opportunities for parents are provided, for example music therapy groups for children include a space for parents to meet. Transport to and from activities is available, if required.

Schools are community-focussed and provide opportunities for children without disabilities to act as mentors to help support disabled pupils.

Existing play facilities are accessible by children and young people with disabilities.

Play work staff are trained to effectively support disabled children within community based provision to provide socialisation opportunities both with other disabled children and with non-disabled children.

5
**Growing up
– puberty
and moving
to
secondary
school**

Event 5: Growing up – puberty and moving to secondary school

People involved with families

Key worker, teachers, school nurse

Where

At school, or at home or other location convenient to the family.

When

Starting during Year 6.

What can we expect?

Adolescence is a critical time for all children and one where problems can begin to occur - the aim at this stage is to ensure that young people have a smooth route into secondary school and receive the information they need to support them growing up.

The key worker and the family meet together with teachers to plan the move to secondary school. This meeting is also used to review existing services and progress towards outcomes.

A review of the plan is conducted during year 7, with the family, key worker and teachers present as part of the annual school review for the young person.

Support for young people is provided during adolescence – sex and relationship education for young people with disabilities and support for families is given via the school and/or school nurse.

True inclusion is experienced – the young person has social opportunities including after school activities, and is actively encouraged to access these. Access to careers advice is available.

6
**Becoming
an adult -
preparing
for the
future**

Event 6: Becoming an adult – preparing for the future

People involved with families

Key worker and transition team – this will include staff from the education department, schools, children and adult health and social services, careers services, housing, leisure, youth services, independent third sector providers.

Where

At school, or at home or other location convenient to the family.

When

Annually

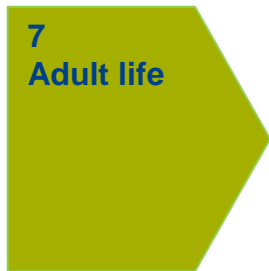
What can we expect?

The aim at this stage is to ensure that the family begins to prepare for the young person's move to adulthood, that they have clear expectations about what options and services are available and are able to make informed choices about the future.

Annual school reviews involve parents and all professionals involved with the family, and look at services and support currently being provided. At these meetings outcomes are reviewed across all areas of the young person's life and support needs for family are also reviewed.

Services are available that together can support a meaningful life for the young person. Families are aware of what services and equipment are available so that informed choices can be made.

In addition to annual reviews, transition planning takes place. Transition planning is person-centred, with the young person's preferences, goals and aspirations taking centre stage. The transition process brings together the people who will ensure that families and young people with a disability can plan ahead for the future as they enter adulthood. The transition plan is focussed on individual needs, regardless of what those needs might be, and agreed with young people and their parents.



Event 7: Adult life

People involved with families

Key worker and transition team

Where

At school, or at home or other location convenient to the family.

When

Age 17 and over

What can we expect?

The aim at this stage is to ensure that the whole family is prepared for the young person's move to adulthood, that they have clear expectations about continuation or changes in services and that the planned move to further education, training or employment is smooth.

Families are aware of any changes to services once the young person reaches age 18, via the key worker. The family are clear about what is to happen as this has been detailed in the transition plan, which will cover the areas of:

- Medical care
- Work, further education, training
- Accommodation
- Support for the rest of the family

Families are in receipt of targeted support and are aware of what is achievable and deliverable. Going forwards, the young person has a suite of options regarding learning, working and leisure activities. Reviews are conducted with families on a regular basis and at least annually.

Where relevant, every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.

6 Information

Information is given to parents along the whole pathway. The right information, given at the right time, at every stage, is very important for parents. Types of information that parents need includes:

- Information about the process of support and care, including what will happen next and what is due to happen when.
- Information about the disability including diagnosis and how it will/may change over time, plus trusted and reliable websites.
- Health care arrangements.
- Services available, including entitlement to services and waiting times.
- Support options including short breaks, counselling and support groups.
- Play, sport and leisure opportunities.
- Financial information.

Information needs to be set out clearly, be up to date, and be easy to get hold of. There is a dedicated website (or set of web pages within e.g. the Council website), supplemented by an annually updated and circulated booklet for those without internet access.

7 Key worker role

The key worker is someone who supports parents along the whole pathway. A key worker is a named person who is both a source of support for children and young people and their families, and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and with professionals, and for ensuring delivery of an inter-agency care plan for the child and family.

The aim of the key worker is to:

- Provide a single point of contact for the child / young person, their family and professionals.
- Work across agencies to coordinate services, to improve the care and support that disabled children and their families receive.
- Enable families to access and understand accurate and reliable information that is provided when the family wants it.

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- Support the whole family to identify their strengths and to identify their needs and the ways those needs could be met.
 - Provide emotional and practical support within a supportive relationship, conducted in the spirit of partnership, with regular contact.

Families should be offered a choice of key worker. The key worker should be a professional who is currently working with, or known to, the family.

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