



## **Getting It Right for Everyone (GIRFE)**

### **Fife Pathfinder Theme:**

*Families with multiple and/or complex needs; and  
young people in transition from GIRFEC to GIRFE.*

### **Phase 1 Engagement April-May 2023**

### **Overall Engagement Feedback**

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## 1.0 Introduction

GIRFE (Getting It Right For Everyone), is a new development programme announced by the Scottish Government, with the purpose of establishing a national integrated practice framework to assist health and social care partnerships in developing greater joint working within the partnership, third and independent sector builds on the already existing adult best practice and the already well-established framework for children, GIRFEC (Getting It Right For Every Child).

Health Boards across Scotland already involved in this development and named 'pathfinders', will test and develop the principles of GIRFE in their area with the people it is designed to benefit, using elements of co-design, and supported by the Scottish Government via a National Design School and learning network.

Five themes were identified to be tested and Fife chose to take forward the theme of **'Families with multiple and/or complex needs including people progressing from GIRFEC to GIRFE - supporting the Child Poverty agenda and transition from GIRFEC'**.

There are two phases to the engagement required for GIRFE:

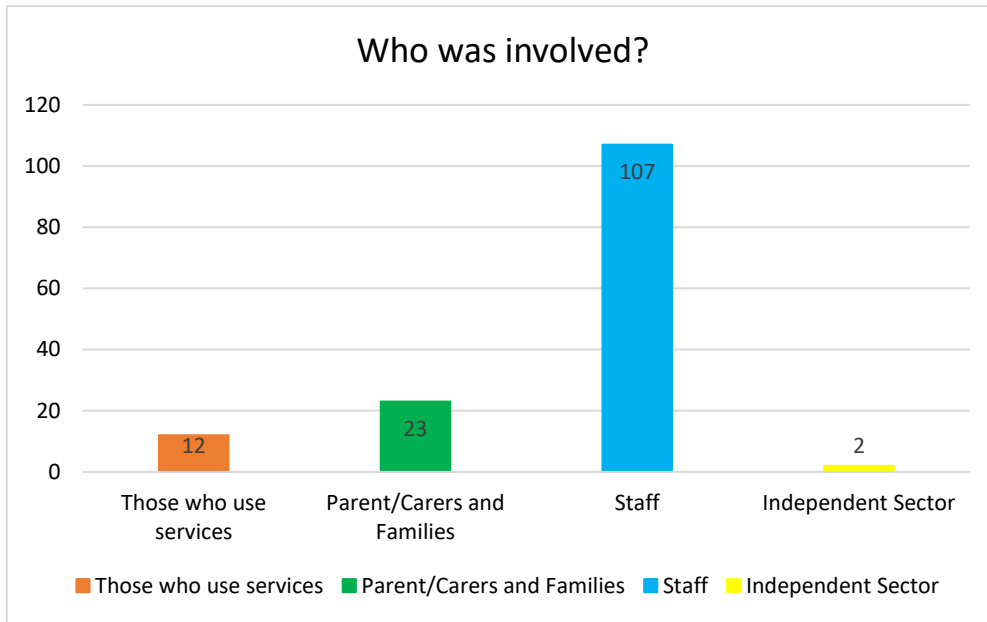
**Phase 1** engage with individual stakeholder groups to identify current challenges they face during the transition phase, what works well, and to open the opportunity up, particularly to parents and carers, and service users, to have their journey and experience heard. This will also include engagement with the Independent Sector, and staff groups across Health services, Social Care Services, and Education.

**Phase 2** - bring stakeholder groups together with elements of co-design, to encourage stakeholders to work together to develop a prototype to be tested by the end of the calendar year.

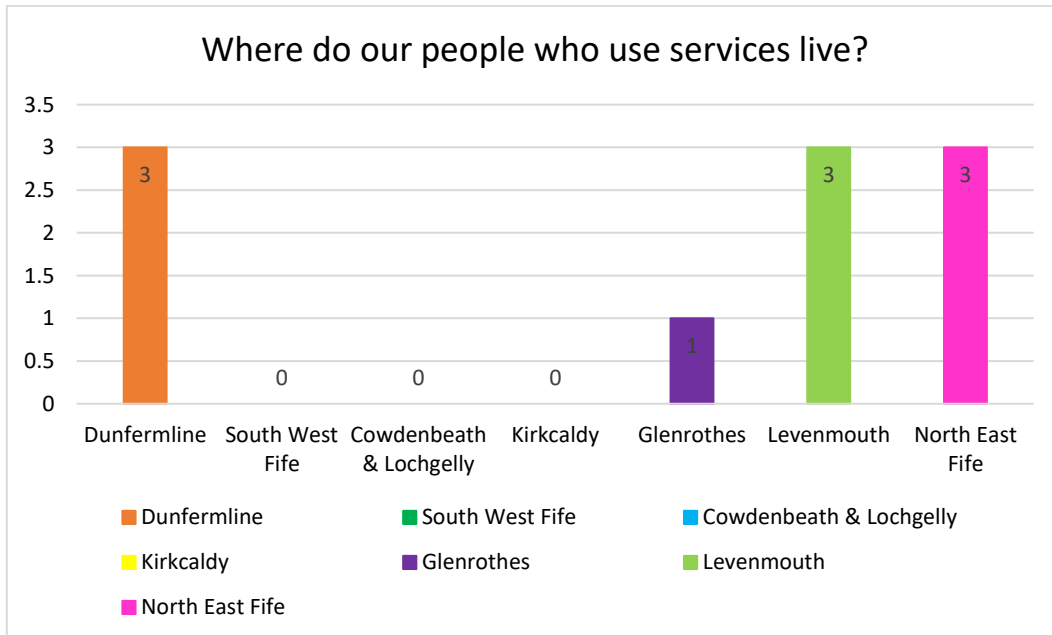
Fife Health and Social Care Participation and Engagement team have been involved with the Fife working group since the beginning as part of the smaller engagement team. An engagement plan was agreed and engagement with key stakeholder groups has taken place over April and May 23.

### *Phase 1 Engagement*

During phase 1, a total of 144 people participated in the engagement sessions. The following chart breaks down participants per stakeholder group; Parent/Carers and Families, those who use services, staff groups, and the independent sector.

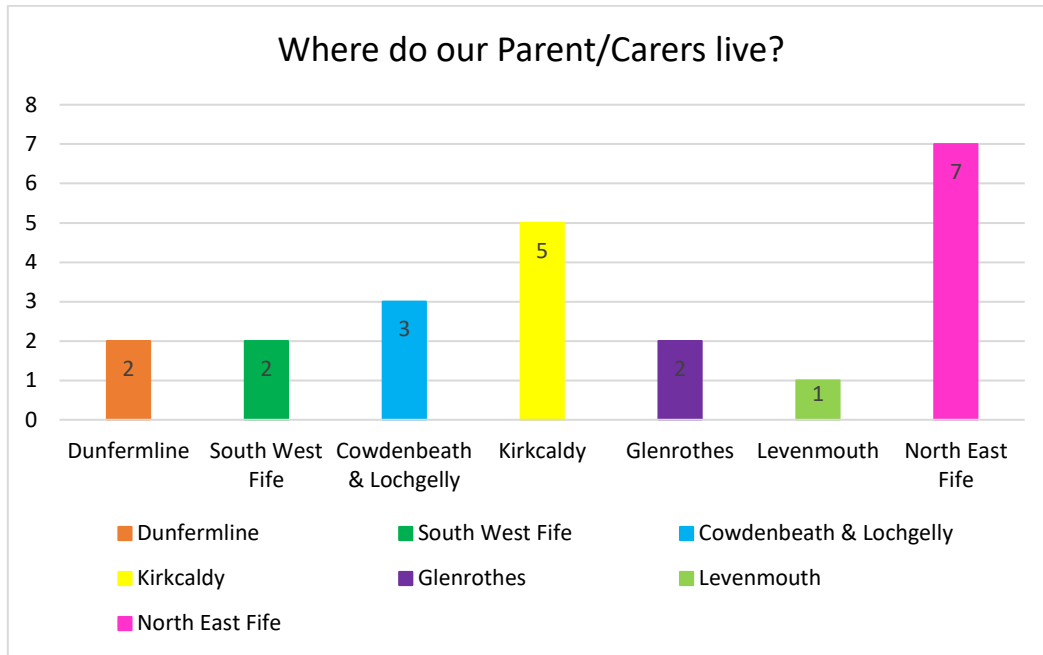


The following chart breaks down where people who use services live:

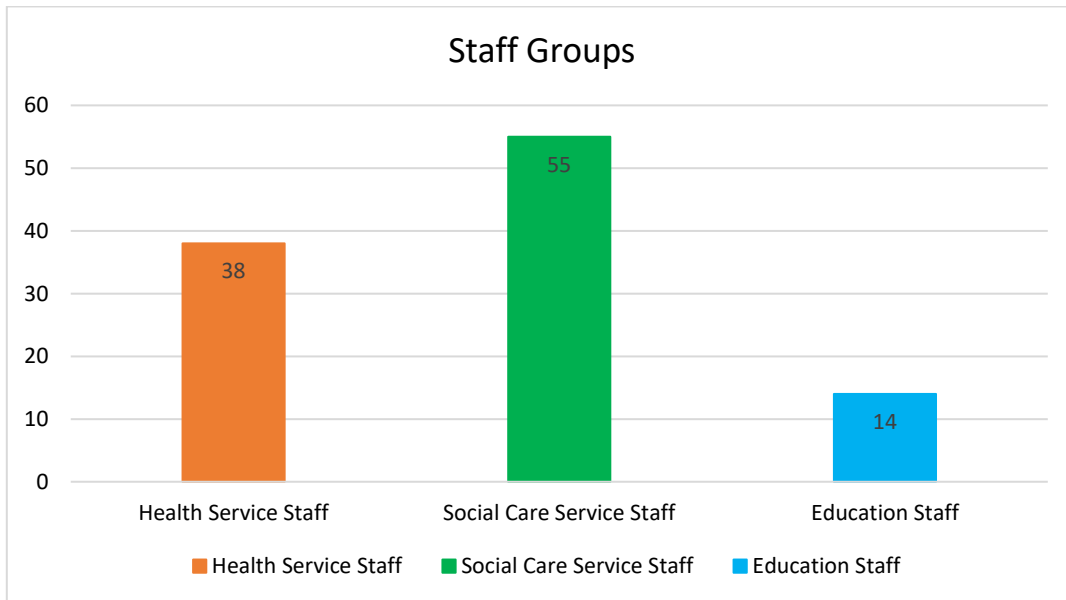




The following chart breaks down where are parents and carers live:



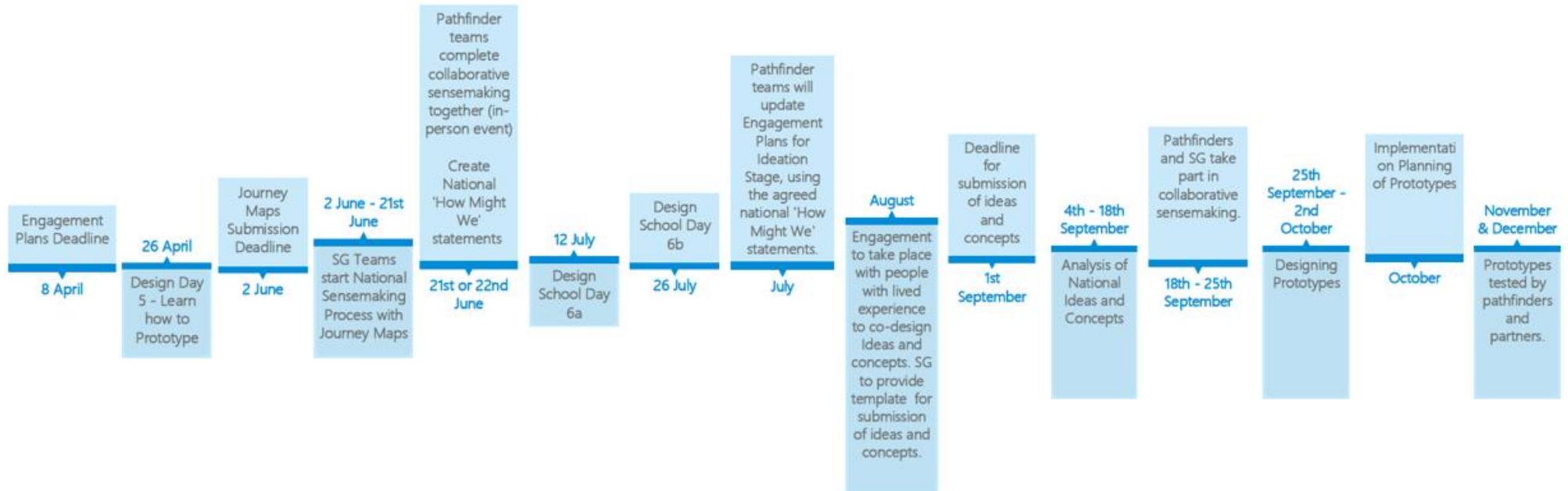
The following chart identifies the staff groups that we engaged with:



The following report will analyse key findings from each stakeholder group with an overall conclusion and identification of key themes towards the end. Included within this report is lessons learned when engaging with each stakeholder group, and overall, as well as the methodology and distribution of invitation to engage.



## The Engagement Timeline





## 2.0 Feedback from Stakeholders

As key stakeholders within this engagement exercise it was important to hear the views from:

	<b>People Who Use Services</b>	<b>Parents/Carers and Families</b>	<b>Staff Groups</b>	<b>Independent Sector</b>
	<i>To find out the challenges they have faced during transition between services and areas they felt went well.</i>	<i>Who often act as an advocate for their family member who receives a service, to find out the challenges they have faced during transition between services and areas they felt went well.</i>	<i>Who work closely with those who use services and their carers and families either in Children's, Adults and/or Older Adults Services, and often during the transition between these, to find out the challenges they have faced during transition between services and areas they felt went well.</i>	<i>Who provide services to those with complex needs and/or learning disabilities, to find out the challenges they face during transition between services, and areas they find difficult when providing a service, but also to highlight any areas that currently works well.</i>
	<b>12 service users participated</b>	<b>23 parents/carers participated</b>	<b>107 staff members participated</b>	<b>2 members participated</b>
<b>Methodology</b>	1:1 interview (with the support of a scribe) at home, or in a small group at school. Service Users spoke through their experience of transition, when they started to talk and discuss finishing school, what their options were, did they have a choice and how they felt about it. All stories were captured on a journey map (appendix 1) which outlines the person, or families, journey highlighting what went well and any challenges they faced. From the information gathered, key themes were drawn for evaluation as well as any gaps in services.	Phase one of the engagement involved agreeing who we wanted to engage with and in what way. Initially it was suggested we meet with groups of parent/carers, but it was quickly realised that because of the emotive subject and the difficulty in getting carer/parents together a 1:1 approach would be most appropriate for that group. When letters were sent out asking for permission to engage with their young people/ adults an invite was extended to speak to them too. Further journey maps (appendix 1) were completed for each parent carer we engaged with.	Service Leads, who were on the GIRFE working group, organised for the Participation & Engagement officers to attend team meetings of any staff involved in transition or people accessing services with a complex need as an adult. There were also three online sessions organised for transition link workers. These were attended by at least two Participation & Engagement officers again one to lead and one to scribe. A general journey map was completed for the group. A Microsoft form was also distributed by service leads for any staff unable to attend the sessions or wanted to provide additional feedback.	It was recognised that staff in the third and independent sector may not have the time or the required digital solutions to take part in much engagement so a drop in was arranged at Auchmuty Learning centre over an afternoon and evening. Unfortunately, no one attended. A Microsoft form was also distributed along with an invitation to one of three online sessions. Journey maps were done as a group for online and each Microsoft form was put onto an individual map.
<b>Distribution</b>	Letters were sent to parents/carers of children in special education or DAS (department of additional support) units, who were about to or already in the process of transition from children to adult services, asking if they would like their children or young adult to engage with us on their experience of transition. Similar letters were also sent through social work to parent/ carers of those who had already transitioned or had acquired a complex need as an adult. Although the pathfinder did not include adults who had not transitioned from GIRFEC to GIRFE, this group were identified as a key voice in understanding their experience of current adult services.	A letter was sent out by education, health, and social work staff to invite parent/carers to engage with us. This was followed up by a phone call or a chat by known staff. When there was a positive response the Participation & Engagement officers phoned to make an appointment at a convenient time and venue (home, local café, council office or school).	Team meetings, online sessions or MS forms were attended/completed by:  <b>Health Services</b> <ul style="list-style-type: none"> <li>• Palliative Care Team</li> <li>• Children and Young Peoples Community Nursing Team</li> <li>• Children and Young Peoples Physiotherapists</li> <li>• Children and Young Peoples Occupational Therapists</li> <li>• Continence Service</li> <li>• Mental Health Services</li> </ul> <b>Social Care Services</b> <ul style="list-style-type: none"> <li>• Social Work Adults</li> <li>• 16+ team</li> <li>• Transition Link Workers</li> <li>• Social Work Older Adults</li> <li>• Self-Directed Support Team</li> <li>• Children with Disabilities Team</li> </ul> <b>Education</b> <ul style="list-style-type: none"> <li>• Staff from Departments of Additional Support</li> <li>• Staff from Special Schools</li> </ul> <b>Independent Sector</b> <ul style="list-style-type: none"> <li>• Staff from the Care at Home Collaborative</li> </ul>	Information regarding the engagement was sent out by service lead from contract and commissioning team and the HSCP Independent Sector Lead to all care at home and care home representatives for distribution to both private and independent.



**Lessons Learned**

People Who Use Services	Parents/Carers and Families	Staff Groups	Independent Sector
<ul style="list-style-type: none"> <li>• It was difficult to engage with people who use services as many parents/ carers said their child/ young person would have no understanding of what we were discussing.</li> <li>• Many were non-verbal so more time would have been needed to create special forms of communication such as talking mats and we would need help from their support workers.</li> <li>• Many parents/carers did not wish their young people to engage due to the sensitive discussion and the fact that the young people were not aware of the upcoming transition as they did not have a future pathway confirmed.</li> <li>• School holidays also lost us much time.</li> <li>• Many of the people who use services that we did engage with had little understanding of what we were asking and why, due to their complex needs and/or learning difficulty they did not understand what choice or not they might have.</li> </ul>	<ul style="list-style-type: none"> <li>• People more likely to engage if letter is followed up with a chat from a member of staff they trust or a phone call in the first instance.</li> <li>• People who are parents/carers of people with complex needs may find it difficult to talk openly about their experience in a group setting and many commented it was more comfortable in their own home.</li> <li>• If you are leading and actively listening to someone you are engaging with, it is much easier to have someone else to scribe so you can give your full attention.</li> <li>• You need to allocate at least an hour to one hour 30 minutes as you could not rush people, they may need a break and their story needed to be completed.</li> </ul>	<ul style="list-style-type: none"> <li>• Group work was successful with staff. They were keen to share their views to help improve the services.</li> <li>• Consulting during team meetings was a good use of staff time and already scheduled in their diaries.</li> <li>• Although journey maps are great way to chart someone's experience, they can be time consuming to complete so time has to be set aside to analyse the notes and to fill in the journey map in a logical manner.</li> <li>• It was felt that we needed further consultation, to include GPs and acute health services.</li> </ul>	<ul style="list-style-type: none"> <li>• Drop-in session for care at home and care home staff did not work. It could be because the venue was in the wrong place, time, or it could be staff did not feel the subject matter was applicable to them.</li> </ul>





The following information is themes identified from the feedback collated through the journey maps from:

	Staff Groups					
	People Who Use Services	Parents/Carers and Families	Health Services Staff	Social Care Services Staff	Education Staff	Independent Sector
<i>How does a person's experience start?</i>	<ul style="list-style-type: none"> <li>Generally, it was a good experience where there is early diagnosis and the right services involved.</li> <li>Third and voluntary services very supportive.</li> <li>Delays in getting the right equipment to meet the needs of the person.</li> </ul>	<ul style="list-style-type: none"> <li>Most parents attended transition meetings in their child's school. There was disparity in what schools offered and when they offered it.</li> <li>Parents/ carers have found their school supportive and helpful but most still had to find out a lot of information for themselves or through other parents.</li> <li>Parents/ carers feel it is confusing during transition because of differences in when health services swap from children to adult services. They also found it difficult to co-ordinate this.</li> <li>Carers of adults usually went through their GP however because of GDPR they were often not allowed to know what was being agreed upon even though they were the ones dealing with it all.</li> </ul>	<ul style="list-style-type: none"> <li>GIRFEC has been successful in children's health services. It ensures good accessibility and meets the needs of most young people.</li> <li>Childrens health services work well in a multi-disciplinary approach.</li> <li>If a child is near end of life when they are due to transition paediatrics will continue to care for them to keep continuity.</li> </ul>	<ul style="list-style-type: none"> <li>Effective communication between schools and social work makes transition easier.</li> <li>Ideally an awareness of children who will be transitioning should be around 14-15 years. There is an inconsistency around this.</li> <li>Waiting lists for services are long.</li> <li>It is difficult to source multiple services a person may need.</li> <li>Transitions vary dependent on peoples need. The change in criteria from children to adult services puts up barriers and mean some people miss out due to eligibility.</li> </ul>	<ul style="list-style-type: none"> <li>Transition discussions start around 15 years, with multi-disciplinary meetings.</li> <li>Schools often support parents with guardianship including awareness of costs-very little advice from social work.</li> </ul>	<ul style="list-style-type: none"> <li>Referrals to Home Care come through social work- families or the individual, people cannot self-refer.</li> </ul>



*How does a person start their engagement?*

	Staff Groups					
	People Who Use Services	Parents/Carers and Families	Health Services Staff	Social Care Services Staff	Education Staff	Independent Sector
	<ul style="list-style-type: none"> <li>Confusion around what was available and what they were entitled to.</li> <li>Found schools supportive and gave time to discuss options for destinations.</li> <li>Felt they were sometimes left out of the conversation.</li> </ul>	<ul style="list-style-type: none"> <li>Parent/ carers often felt very anxious about losing the key people they had built a relationship with.</li> <li>There was also anxiety around the change for their young person if they had little understanding of why things had to change.</li> <li>There were multiple assessments, many new procedures and lots of new staff to meet in both social work and health. Parents felt they had to go through their story and their young person's needs too often.</li> <li>Guardianship was mentioned by many. Some knew about it, but others found out quite late leading to late allocation of adult social worker. It also comes with a cost. Parents/ carers want to know why they have to pay to look out for their own child?</li> <li>Parent/ carers often given a list of destinations which they had to go through, phone or visit. Many of the services were closed, had long waiting lists or were inappropriate.</li> <li>Assessments and funding are not recognised from other regions/ countries. This leads to a delay when parent/ carers can be left without help for a long period of time.</li> <li>Assessments often conclude that adults need specific care but there is often no one to do it. Social workers also feel the frustration.</li> </ul>	<ul style="list-style-type: none"> <li>Conversations that start before assessment can allow for early intervention and prevention.</li> <li>Referrals are simple and straightforward in children's services, they are based on the individual and unlike adult services there is one point of contact.</li> <li>Duty of care in child protection means 'did not attend' appointments are followed up and there is a responsibility to ensure parents/carers can get the children to appointments.</li> <li>There is lack of training in adult services on procedures and equipment that is available in children's services.</li> </ul>	<ul style="list-style-type: none"> <li>Education pathways are ideal however college capacity and criteria make this now a challenging route.</li> <li>A lot of gaps in service since covid because of this there is a feeling of letting people down.</li> <li>Social workers feel they have to manage the expectations of parents and families due to lack of understanding.</li> <li>There are many more resources and services in for children than adults.</li> <li>There are long waiting lists for the services that do exist.</li> <li>There is a young people's team which should allow a smooth transition for children and young people, but where there is a health need they go straight into the adult's team even though there may be more support needs.</li> </ul>	<ul style="list-style-type: none"> <li>Parents often choose what they feel is the right pathway for their child with support from the MDT and this involves the child where possible. This stage highlights how limited college courses and other services are in Fife.</li> <li>When children are going to college when they leave, they spend one day per week while still at school there to get used to the environment, build friendships, and meet tutors. This experience is usually very positive.</li> <li>Adult social workers/ link workers not usually involved until a couple of months before the child leaves school.</li> </ul>	<ul style="list-style-type: none"> <li>A homely setting is much better for both patient and carer when assessing.</li> <li>Takes in both physical and mental health.</li> <li>Regular assessment to ensure care is suitable.</li> <li>The decision is often made for the person by social work or family members.</li> <li>There is limited capacity for under 65s' in care homes.</li> </ul>



*How does a person experience the service?*

	Staff Groups				Independent Sector	
	People Who Use Services	Parents/Carers and Families	Health Services Staff	Social Care Services Staff		Education Staff
	<ul style="list-style-type: none"> <li>• Good support from support groups and peers.</li> <li>• Some felt services rush through changes this did not move at the pace of the person's needs.</li> <li>• Services cut due to covid and never reinstated.</li> <li>• Resources such as carers not able to meet people's needs such as time allocation and services limited particularly in NE Fife.</li> <li>• People liked visits at home from services as it felt less formal, but they often were unsure what the appointments were for.</li> <li>• DAS pupils reported anxiety over changes, too many people and different environments. Often as a result of their experience of bullying in the mainstream school.</li> <li>• Fife Forum and Fife Voluntary Action website were reported to be difficult to navigate</li> </ul>	<ul style="list-style-type: none"> <li>• Young people in DAS units often attend college one day per week in their final year. This is seen as positive, but it is supported by PSA's and this support is often not available when they do go to college.</li> <li>• If a young person has specialist medical needs, there are often issues trying to find appropriately trained staff in adult services to take over from children's services.</li> <li>• Due to closures, it is difficult to find places at day centres. The criteria means they may only get two days which has an impact on parent/ carers who work and the routine and structure for the young person.</li> <li>• Parent/carers often hear their young person's assessment and plan has to go to a panel to have the budget agreed. Many feel they should have a say in this or at least be part of the conversation.</li> <li>• Respite is almost impossible to find in Fife. This means parents and carers are struggling with their own mental and physical health.</li> <li>• Parent/carers often go to visit day services in Perth and Stirling as possible destinations however it is difficult to get a place and can be a long commute. Why is there no equivalent in Fife?</li> <li>• Pupils are often a few weeks from leaving school and still have no destination.</li> <li>• Young adults with autism and need 1:1 support find it particularly difficult to access services.</li> </ul> <p>Adults with acquired needs often end up in care homes even though they are under 65 and want to stay at home because it is cheaper and easier than getting staff.</p>	<ul style="list-style-type: none"> <li>• Some services have an operational lead who has sight of both adult and children services, this provides continuity and consistency.</li> <li>• Childrens services have criteria that is lower than adult services.</li> <li>• Some services will stay with a child until they are fully transitioned some just pass over.</li> <li>• There is a lack of resource in learning disabilities adult team and no resources in Fife for those with complex care needs.</li> <li>• Young people being pigeon-holed into inappropriate adult services.</li> <li>• Workload means, it is hard to attend transition meetings.</li> <li>• Families find it hard to move from wrap around care and a single point of contact to multiple specialists and support functions.</li> <li>• In some cases, there is no like for like service in adults, so families are left to pick up the short fall.</li> </ul>	<ul style="list-style-type: none"> <li>• Different professionals have differing views on correct pathway.</li> <li>• There is scope for creativity.</li> <li>• Staff feel like they can't provide a service which is based on the morals, values, and ethics of social work due to lack of options and high level of criteria.</li> <li>• Self-directed support should allow choice and flexibility but again limited by lack of services.</li> <li>• Feels like a no man's land between 16-18 years as there is no clear transition date for all services.</li> <li>• Parents under pressure to fill gaps in services.</li> <li>• Parents feel the support in children's services are not replicated or near to in adults' services when the needs of the young person remain the same if not worse.</li> <li>• Parents with loudest voices are always heard and often get the right services. Parents who are less confident or can't advocate for themselves get less!</li> <li>• Support services need investment in Fife-there is nothing for young people with the most complex needs.</li> </ul>	<ul style="list-style-type: none"> <li>• Long waiting lists for befrienders or personal assistants mean young people can't really move on.</li> <li>• Level of care drops after leaving school- less supervision, nobody to keep an eye on vulnerable individuals who need that extra support. Real worry to school staff and parents.</li> <li>• Just because the child is now of 'normal' school leaving age does not mean their mental capacity is.</li> <li>• Not enough resources in Fife for young adults.</li> </ul>	<ul style="list-style-type: none"> <li>• There is always a choice for people to leave if they wish to do so and go into community-based services.</li> <li>• Again, regular assessments take place to ensure care home is the right setting for the individual.</li> <li>• For those with capacity there is a lot of stigmas attached to being in a care home.</li> </ul>



*How does the experience develop for a person?*

	Staff Groups					
	People Who Use Services	Parents/Carers and Families	Health Services Staff	Social Care Services Staff	Education Staff	Independent Sector
	<ul style="list-style-type: none"> <li>Where respite is available for adults it is greatly valued.</li> <li>Good communication between schools and colleges works well with pupils transitioning spending one day or one-half day at college per week. This gives a chance to get used to the college environment, meet peers, and build relationships with staff in a safe supported manner.</li> <li>Transport support and costs differ between children and families and adult services.</li> </ul>	<ul style="list-style-type: none"> <li>Parents/ carers felt that a person with complex needs does not get better, in fact they often require more help as they get older. Services seem to get less.</li> <li>Parent/ carers feel uninformed and desperate for support.</li> <li>Parent/carers feel that funding and services are not equitable even though there is a set criteria. Those who are most articulate, educated, and willing to put up a fight, get the most. They feel this is not a fair system, what about those parent/carers who have learning disabilities or are not strong enough to make their voice heard.</li> <li>There is little choice in services for young people and families.</li> </ul>	<ul style="list-style-type: none"> <li>Services do try to promote independence and empower people to do things for themselves.</li> <li>Do try to give choice about services but little available.</li> <li>Learning difficulty does not meet criteria for some services but no alternative.</li> <li>Families have direct access to hospital and supplies then in adult services they have to go through GP, A and E and district nurses. Everything takes longer.</li> <li>There is a lack of support to families including short breaks and respite.</li> </ul>	<ul style="list-style-type: none"> <li>Services have been cut and service delivery has changed in day services from in house to community based, this has meant that lots of people can't access this service as not suitable for their needs.</li> <li>Staff try to have a holistic approach but services limit this.</li> <li>Social work undertakes regular reviews- GPs do not attend these.</li> <li>Social work staff are the main contact for families who are nervous and anxious and have no positive pathway in place. It is difficult for staff to deliver this message that there is little or no choice.</li> <li>There is a challenge around guardianship not being in place for self-directed support.</li> <li>National shortage of resource and services for people.</li> <li>Independent services mainly offer 1:1 support, this limits social interaction.</li> <li>Severe lack of training in adult nursing in the community-limits choice of service provided.</li> <li>No resource for adults with complex needs to have respite, only care home beds.</li> </ul>	<ul style="list-style-type: none"> <li>Parents need more support during and after transition. When transition happens, they feel like they are left alone to get on with it or' fall off the edge of a cliff'</li> </ul>	<ul style="list-style-type: none"> <li>Good relationships are built with the MDT (including GP), families and the person.</li> <li>Activities in care homes are choice based.</li> <li>Referrals to other services can often take a long time as have to go through GP- often feels like time wasted going through middleman.</li> <li>Very little information provided to families around finance and legal policies.</li> <li>Social work should visit more often.</li> </ul>



*How does the experience end for the person?*



People Who Use Services	Parents/Carers and Families	Staff Groups			Independent Sector
		Health Services Staff	Social Care Services Staff	Education Staff	
<ul style="list-style-type: none"> <li>• There are worries about funding and services being taken away.</li> <li>• They feel there are conflicting messages.</li> <li>• Those going to college generally look forward and are confident about going to college but sad losing friends who go different ways due to availability/ eligibility of different services.</li> <li>• If the person goes into hospital for a period of time there is a risk that their services are removed and have then go through another process for them to be reinstated.</li> </ul>	<ul style="list-style-type: none"> <li>• Although parent/ carers report how caring most staff are, it is difficult to build relationships as staff particularly in social work and social care seem to change a lot.</li> <li>• Parent/ carers feel they are accepting services that are not really appropriate but it's all there is.</li> <li>• Parent/ carers really worry about what will happen to their young person if something happens to them. They feel there is just nothing.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents/ carers feel very anxious about transition.</li> <li>• Families often have to source support outside Fife.</li> <li>• Third sector and charities are often able to provide services which were available in children's services which are not replicated in adult services.</li> </ul>	<ul style="list-style-type: none"> <li>• The care sector is not an appealing job, too many vacancies, staff shortages and there is a constant back filling of posts.</li> </ul>	<ul style="list-style-type: none"> <li>• Those with really complex needs mostly end up house bound after 'transitioning' because there are no services to cater for their complex needs.</li> <li>• Those who get a personal assistant go to cafes or shopping centres which does not provide much stimulation. There are no community bases they are eligible for.</li> <li>• What happens at the end of college, no clear pathways so parents have the fear of transition constantly on their mind.</li> </ul>	<ul style="list-style-type: none"> <li>• The pathway for the individual is discussed with them and a plan put into place-whether it be palliative or home care.</li> <li>• Care home funding often go on building maintenance rather than on things for the residents.</li> <li>• Residents should be able to visit care home before a decision is made.</li> <li>• Hospital discharge often feels rushed.</li> </ul>





### 3.0 Supporting Engagement – Local and National Strategies and Consultations

Various local and national papers support the development of GIRFE with a focus on the transitions between services. A list of these with links can be found below.

Document	Link
Transitions to Adulthood for Disabled Young People: Literature Review	<a href="https://www.gov.scot/publications/introduction-to-adulthood-for-disabled-young-people-literature-review/pages/introduction-to-adulthood-for-disabled-young-people-literature-review.aspx">Introduction - Transitions to adulthood for disabled young people: literature review - gov.scot (www.gov.scot)</a>  Synopsis:  Transition to Adulthood - Review
SDS Information and Fife GIRFE	 Transition GIRFE and Self Directed Su

### 4.0 Conclusions and Overall Key Themes

Phase 1 of the GIRFE engagement identified key themes from each stakeholder group which have been analysed and outlined throughout this report. The following section identifies key themes that were highlighted across all stakeholder groups.

#### Key Theme - Transition into Adult Services

During the “transition” phase, all stakeholder groups agreed that the transition between children into adult services can often feel like those who use services, and their carers and families, often feel like they are ‘falling off a cliff’. Staff in health, education and social care services, and the independent sector echoed this and added they know how difficult the transition process is and can find it demoralising. Concerns included lack of resources, vulnerability of young people going into communities along with a reduction of stimulation. There is often a significant impact of move from wrap around care and single point of contact (Children’s) to multiple specialists, and support functions in adult services. All stakeholder groups also agreed that there is a lack of consistency in age across services and to continue this idea there is often a lack of understanding that many young adults in transition are adults in age only and often remain childlike and very vulnerable. Lastly, it was echoed across stakeholder groups that the criteria for moving from adults to older adult’s services is different which often results in someone losing a service as they are no longer eligible to receive this even if they have received it until they are aged 65.

#### Key Theme - Resources

Resources was another key theme that emerged across stakeholder groups and the recognition around the lack of both locally in Fife but also nationwide. As a result, this



often means people transfer to Edinburgh, Dundee, or Perth to access services which is more costly financially and timely. Stakeholder groups agreed that there is a lack of suitably trained staff and care roles need to be more appealing with better wages and T&Cs to encourage care as a career path. Consequently, there is a lack of respite and short breaks available to support families when they need it the most which often results in additional support and health concerns around mental health and wellbeing. However, where respite is available stakeholders agreed it is a huge positive for families and relieves some pressures and stress despite the length of time.

### **Key Theme – Support for Families**

Support for families and carers was a topic that was widely spoken about across stakeholder groups and was recognised as a top priority by staffing groups. Staff across education, health, and social care services and the independent sector felt parents are often left to get on with life while waiting for services to be put in place. Carers and families agreed with this, and some identified they had given up working to provide full-time care for their family member when they left school. This shift was recognised not only to impact those who use services and their carer but also the wider family creating a feeling of isolation and loss of identity. Staff groups agreed with this and added that it feels there is often an expectation that parents/carers and other family members will pick up the slack where resources aren't equipped or able to provide a service. In addition to this it was echoed across stakeholder groups there is often a perception of too many barriers, or red tape, around eligibility for grants and funding, and accessing services out with Fife which adds to the pressures and additional stress and anxieties of families.

### **Key Theme – Support for Staff**

Continuing the theme of support, the recognition of support for staff was raised across all staff stakeholder groups. There is a real concern over the lack of resources from a local and national perspective. Stakeholders suggested there is a focus on solving current issues and pressures across Health and Social Care services rather than looking at the bigger picture and planning for the future. This has resulted in staff anxiety around the vulnerability of adults with learning disabilities going into communities and a lack of stimulation and reduction in social contact and peer support as a consequence. A general feeling of lack of information and understanding is felt between some services and not knowing where there is overlap of services.

### **Key Theme – Relationships between Staff and Families**

However, stakeholder groups did agree that some things do work well. It was agreed that Children's Social Workers and Health Staff build up a good and trusting relationship with the child and their families and having one point of contact in Children's Services works very well. Where services can be flexible and creative to meet the individual's requirements, it was agreed families feel their family member gets better outcomes. Education was also highlighted to be supportive towards families with the discussion around transitions and multi-disciplinary team meetings, and around getting Guardianship in place. It was recognised other services often take



the initiative before the child is due to transition to start the process to try and get things in place as best they can and in a timely manner. All stakeholder groups agreed that GIRFEC and the SHANARRI indicators work well in practice and felt GIRFE would benefit from following a similar framework where possible.

### **Key Theme – Communication between services and families**

In some services there is one service lead for Children's and Adult Services, for example Physiotherapy, and this works well as the service lead has insight into how both services work and this ensures a smooth transition. Excellent communication between Children's services was also echoed across stakeholder groups. It was agreed that where Adult Social Work can mirror the package of support as provided by Children's Social Work this also works well and ensures support for families and a smoother transition between Social Work teams. Recognition around regular assessment was identified as this supports and highlights a change in circumstances as the person progresses throughout their life ensuring services and care plans are updated as appropriate.

Lastly, all stakeholders agreed that where college is deemed suitable, this is a good pathway to continue education and continue to develop life skills. It was felt that more educational services should be readily available to ensure the best quality of life and to promote independence and development where possible.

General discussion recognised many modern-day struggles in Health and Social Care services may be a consequence that because medicine has advanced so much, many people are living with their disabilities for longer than expected. The advancement of medicine has not been aligned across services putting additional pressures on today's services.

Stakeholder groups provided their feedback on the theme "in an ideal world" which has been captured and illustrated in Appendix 2.

The findings from phase 1 will support and inform phase 2 of engagement which is due to take place during Autumn 2023.

#### *4.1 Overall Project Lessons Learned*

Lessons learned have been identified per stakeholder group however some overall lessons learned have also been identified which are outlined below.

- GP voice missing from engagement.
- Need to be able to hear quieter voices where there may be more complex issues than what appears on the surface (e.g., in areas of deprivation, parents who also have a learning disability, etc.)
- Additional support materials from Scottish Government around carrying out engagement and the emotional impact that could be experienced by staff carrying out engagement – recognising triggers around sensitive areas of discussion.





## 5.0 Appendix

### Appendix 1: Journey Map Template

#### Current experience (as-is) journey map

A journey map captures an experience from a person's perspective.

The person whose experience is captured is

	How does a person's experience start?	How does a person start their engagement with a service?	How does a person experience the service?		How does the experience develop for the person?		How does the experience end for the person?	
<b>Draw or use icons to show what the person does.</b>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>	<div style="border: 1px solid black; width: 100%; height: 100%;"></div>
<b>Describe what is happening.</b>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>	<div style="background-color: yellow; width: 100%; height: 100%;"></div>
<b>What are the good bits?</b> 	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>	<div style="background-color: #90EE90; width: 100%; height: 100%;"></div>
<b>What are the bad bits?</b> 	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>	<div style="background-color: #FFB6C1; width: 100%; height: 100%;"></div>
<b>Does this step cover the GIRFE principles?</b>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>	<input type="checkbox"/> Focused on an individuals needs <input type="checkbox"/> Focussed on individuals current situation <input type="checkbox"/> Early intervention <input type="checkbox"/> Joined-up working/info. sharing <input type="checkbox"/> Based on human rights <div style="text-align: center;">✓ ✓ ✓ ✓ ✓</div>



Appendix 2: In an Ideal World

