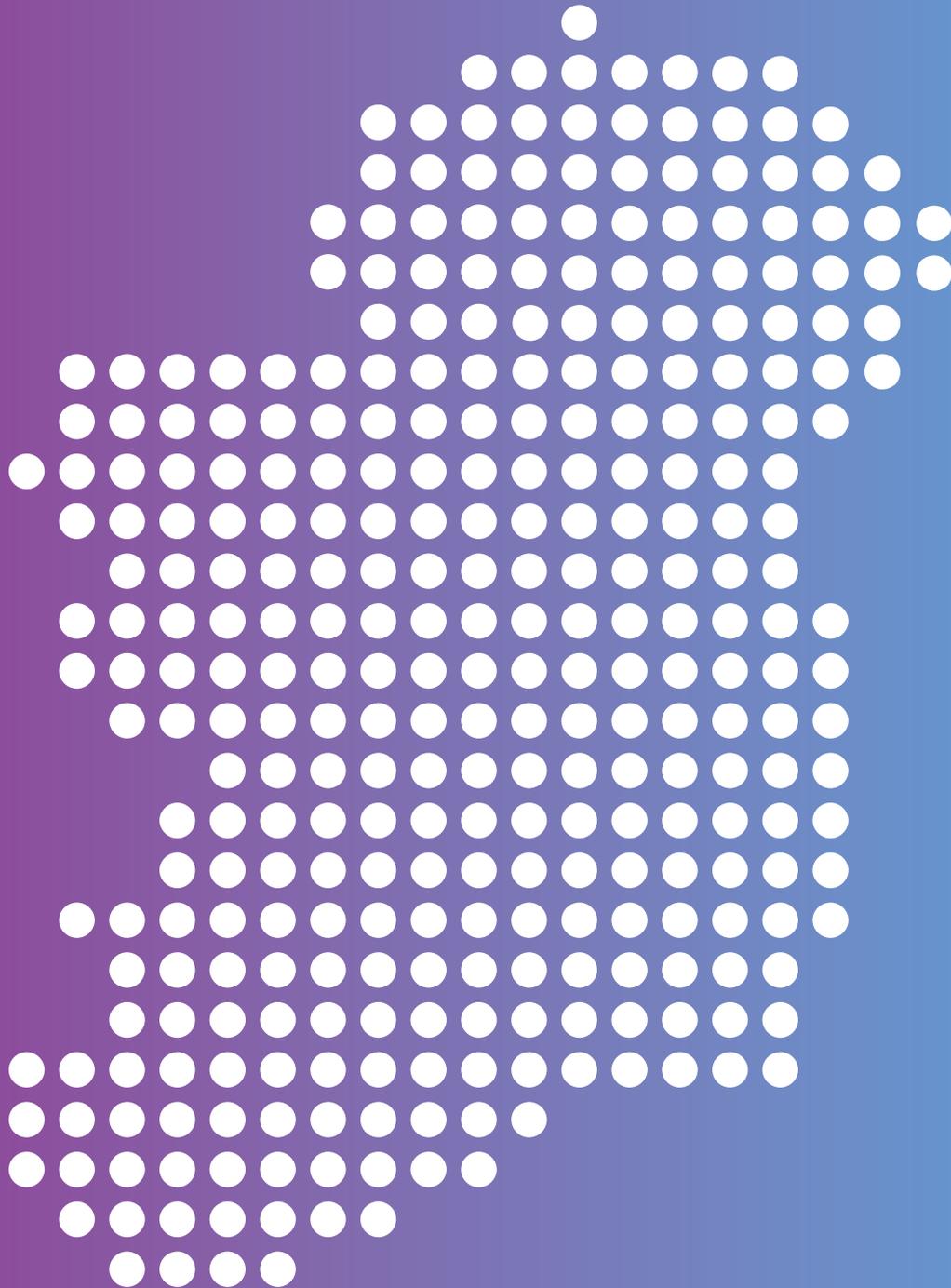


# TRANSFORMING LIVES

Progress Report 2016

Supporting Person-Centred Disability Services



Transforming  
Lives



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive



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## FOREWORD

In Social Care Services we are focused on enabling people with disabilities to achieve their full potential. We are supporting people to live ordinary lives in ordinary places, as independently as possible while ensuring that the voices of service users, and their families, are heard and that they are fully involved in planning and improving services to meet their needs.

To progress this, and to build on what we have achieved to date, we are continuing to reform our disability services. We are working to develop sustainable ways of providing services that ensures positive outcomes for service users while making the best use of our resources and delivering best value for tax payers.

Through the *Transforming Lives* programme, a key priority for us is to continue to deliver on the strategic aims and recommendations of the significant work and research of the ‘*Value for Money and Policy Review of Disability Services in Ireland*’. Specific elements of this will be implemented through our services and those we fund, while other initiatives are implemented through the Transforming Lives Programme working group process in collaboration with the Department of Health (DoH).

Since 2012 there has been a sustained national collaborative effort with the DoH and across the disability sector to bring about a

fundamental change in disability services in Ireland. Although there are challenges, much positive progress has already been made. We welcome, for example, the newly established Taskforce on Personalised Budgets set up by the Minister for Disabilities. This was established under a Programme for a Partnership Government as a key element of the Government’s commitment to give people with disabilities greater control, independence and choice in terms of HSE funded disability services.

There is of course, more to be done. In 2017, under the *Transforming Lives* programme, and in line with the wider health service improvement programme, our six priority strands of activity will be further progressed. Underpinning all of our work is the goal of improving the health and wellbeing of the population and of ensuring that the services we deliver are safe and of high quality.

*Transforming Lives* provides the framework for doing this and for putting policy into practice across the key reports — *Time to Move on from Congregated Settings* in respect of residential centres, — *New Directions* programme to improve day services, and — *Progressing Disability Services for Children and Young People*, which is focused on improving therapy services for children.

This year *Transforming Lives* will also; support the work of

the Taskforce on Personalised Budgets, complete a national Future Needs Assessment report, start a consultative process for service users in line with recommendations of the Plan for Effective Participation and, develop on-line information and advice on disability services for service users, families and the community.

*Transforming Lives* is testament to the contribution of service users, their families, local communities, those working across the disability sector and the commitment to tackle the real and significant challenges in a joined up way. Together we can, and are, transforming lives and supporting people with disabilities to live full and meaningful lives in their communities.

Pat Healy,  
National Director Social Care  
& Programme Sponsor, Social  
Care Reform

## TRANSFORMING LIVES

“What it means to me”

## SERVICE USER STORIES

### Maja

Maja is a twenty year old young person, she is deaf and communicates through Irish Sign Language. Maja is originally from Poland and moved to Galway when she was eight. She attended secondary school in St. Mary's School for the Deaf in Dublin and returned to Galway to her family last June.

Maja also has a visual impairment and a learning difficulty. On return to Galway Maja engaged with DeafHear services and was matched with a Deaf Mentor, Joan. Maja meets with Joan on a weekly basis, attends an art group in DeafHear and also attends the Deaf Club on occasion. The connection between Joan and Maja is imperative as sign language is the natural and preferred language of both ladies.

On returning to Galway, Maja was unable to express her wishes for the future. Since engaging with Joan there has been a noticeable improvement in Maja's confidence. Maja can now travel independently in Galway City and is able to express herself and make her needs known. She has become involved in the Deaf Community in Galway and this has improved both her language skills and her knowledge base.

Maja is looking for a HSE placement that fits in with what she wants for her future and services are working together to make this happen. While this is being worked on Maja is continuing to learn on a daily basis from Joan; she is gaining knowledge, independence, practical and social skills. She is learning all of these skills through her first language, Irish Sign Language. Her confidence is growing and she is identifying personal goals and wishes for her future.



above: Maja

### Cerri

Cerri was born in 1987 and entered Adult Services Dun Laoghaire in January 2008 directly from the Enable Ireland School in Sandymount. While attending Adult Services a key challenge for Cerri was dealing with her acute anxiety. This left her very dependent on members of staff in order to perform tasks and/or go out into the community, including crossing the road. Over time, with support from staff, her anxieties lessened and with support and encouragement she attended classes in a nearby Vocational Education Committee (VEC) Community facility. However, three years ago a big breakthrough came about when the HSE funded a proposal from Enable Ireland which allowed Enable engage a behaviour psychologist to work with Cerri. With her help, and the help of Enable staff, Cerri began to understand her anxieties and fears. Since this key intervention Cerri has become a much more confident and self-contained woman who is out and about in the community on her own, travelling independently and is a very different person at home with her family than she was prior to the intervention. Two years ago having commenced a National Learning Network (NLN) Access Programme in Bray, at Cerri's request she transferred to RehabCare in Bray where she continues to thrive and hopes someday to be able to work part-time.

## Kayleigh

Kayleigh is twenty two, a student and lives in Dublin. Kayleigh is a young woman with a physical disability and uses a power wheelchair. Kayleigh has been actively involved in Irish Wheelchair Association's (IWA) Youth Services since she was fourteen. This experience has boosted her social life and given her a sense of personal fulfilment, providing her with the opportunity to "improve my social skills and open the door to making friends and having new experiences."

Over the past few months, Kayleigh took on the challenge of Youth Club leader, becoming involved in organising the Youth Club activities and working alongside other young people with physical disabilities. Kayleigh says "This has given me a whole different perspective on things. Making someone else's day better can give you a great sense of personal fulfilment".

Opportunities to mix with able-bodied teenagers can be limited, particularly for individuals who do not attend mainstreams schools. Irish Wheelchair Association's (IWA) Youth Club integrates with other, able-bodied, youth clubs within the community. "At first, some of the teenagers from the other youth club were nervous about talking to teenagers in wheelchairs, but it gave them a chance to see that there are a lot of similarities between us; in fact, I doubt they even see the chairs any more" Kayleigh explains.

Kayleigh is also involved in delivering disability awareness workshops, an interactive experience designed to increase the confidence of participants to work or engage with young people with physical disabilities. The workshops are delivered in a wide range of settings and involve co-facilitation by young IWA members and IWA Youth Services staff.

IWA has a range of youth services and activities around the country. The services cater for young people with physical disabilities to assist them to explore their interests and interact with other young people. The aim of IWA's Youth Service is to enable younger members to involve themselves consciously and actively in their own development and in the development of society. The youth service activities are also designed to involve our young members in their local community, and activities include; youth clubs, sports clubs, swim teams, and also holiday or respite breaks.

## Siun

Siun is sixteen years old. Siun has cerebral palsy, a profound intellectual and physical disability and is medically frail. Attendance at school is sporadic due to poor health and frequent hospitalisations. Siun requires twenty four hour care and receives all her nutrition through a peg tube. A Home Sharing family provides two overnight breaks per week to Siun. Her family have described this support 'as a lifeline to them'. To ensure a safe respite placement significant training was provided to the Home Sharing family by the clinical nurse specialist with the support



above: Kayleigh McKevitt

of the paediatric hospital. Regular contact is maintained with the Home Sharing family by the clinical nurse manager and the social work team leader.

## Mark

My name is Mark, I moved out of Cluian Fhionnian where I had no independence, little or no choice over my life from when I got up in the morning to what time I went to bed. In fact I had too much support and felt as if I was being watched all the time, my freedom was limited and restricted. I was told:

What time to eat;

What to eat;

What time to go to bed;

What time to get up;

No choice what to watch on the T.V;

What to buy in the shops;

What time to go out;

What time to come back.

I moved out to a new home called Fortfield where the staff gave me the support I wanted, not what they felt I needed. I had choice and independence to make my own decisions every day. I had support and choices to learn to shop, cook, clean, pay my bills and live my life, learning to take responsibility for me and my life. I learned quickly. My confidence grew and my freedom opened a whole new life for me and in a short time I was able to move into my very own home.

Now I live on my own in my own home in Edward Court. I decide and make the choice when I want support. I've joined local groups in my local community, made friends and am part of my local community. I attend a day service of my choice. I've even been abroad on holiday and am planning to go abroad again this year. My dreams and goals have come true, my life has changed beyond my dreams. I am confident independent and enjoying my life to the full.

## Tim

My name is Tim, I lived in a locked ward for a very long time, too long. I didn't like living there as it made me feel sad and lonely. I didn't feel safe, my things kept getting lost and broken, my clothes would get lost and go missing when they went to the laundry. I didn't have a lot of choice over things in the ward or my life. I missed my friends, family and my home town.

The transition team came and started working with me. I told them I wanted to move out in a year, we talked about me, what had happened to me and what I wanted for the future. I wanted a home of my own back in my home town near my family and friends.

I moved out just over a year later into my own home which is a one bedroom house in my own home town where I was born and lived my childhood. I love being back home and having more

independence, and I can make the choices to do the things I want to do everyday. Since I moved into my local community I have changed my day service to one I really like. I see and visit my family every week and have a great time with my friends and neighbours. I feel safe and secure in my new home. I have all my personal belongings around me and I know they are safe and secure. My life is better than ever and I am delighted that my life has changed and I can live my life how I want to with the support of my family and friends.

## Brian

Brian is a young man who has recently moved from a high support unit in a residential campus to his new home in a housing estate close to the centre of town. The house he shares with two other residents is a recently built bungalow nestled at the end of a cul-de-sac. Internally some discreet adaptations were made to the home to suit the three residents and an extension was added to accommodate a larger utility room and a second sitting area, which ensures it is a home that meets the support needs of the residents, whilst still being an ordinary home in an ordinary place.

Prior to moving to his new home, Brian had been living in a high support unit on an emergency basis for over a year. As this placement was deemed inappropriate, the service spent a significant amount of time working with Brian, his family, multi-disciplinary supports and an independent advocate in order to plan how Brian could best be supported to return to living in the community. As Brian needs time to adapt to new situations and routines, the service in close consultation with his family, worked to build Brian's confidence to enable him to leave the unit and the campus, so he could move into his new home. In order to maintain continuity, Brian's day service routine was not altered at all initially.

It is now several months since Brian moved to his new home and we (HSE & Carriglea Personnel) have arranged to meet Brian back on the campus, where he is spending some time today. Brian sits with us as we are talking alongside some of the staff that support him during the day. After a while Brian chooses to leave and goes off to do a job with a colleague. The staff member remarks that this is something he has chosen to engage in every day and that doing small jobs is important to Brian, giving him a role he is proud of. It is noticeable that apart from bringing continuity to Brian's day, attending the day service also allows Brian to spend time with a peer group who are similar in age and with whom he shares common interests.

More and more, Brian is spending time out in the community, and the staff involved in the day and residential services work closely together to support Brian in reaching his personal goals. An example would be going grocery shopping in town and attending cookery classes in the day service, that link to Brian helping with meal preparation when he returns home. In many ways, Brian is just like many other young people who leave home and who develop skills in terms of domestic chores and activities of daily life!

## Helen

Helen is a middle aged lady who lived at home for quite a time before entering residential services as an adult. Helen lived for many years on a congregated campus. Before her move to the community she was living in a unit with up to eight other people, all of whom had significant support needs. Helen has an intellectual disability and PKU, which is a rare genetic metabolic disorder that must be managed by following a highly restricted diet. She requires a high level of support.

Living within that congregated setting Helen exhibited behaviours that challenge. Helen has now moved to a purpose built home in the community, that she shares with three other people. All the residents have their own specific support needs which include a mix of physical and sensory and intellectual disabilities. Careful planning with each person, their family, advocates and key workers were crucial to agreeing that these individuals would enjoy and benefit from living together. Helen's new home is a bespoke house that has been built just outside of the local town. The house was designed specifically with the current residents in mind, so there is good circulation space and fully accessible communal areas. Each person's bedroom is designed to meet their needs and styled to individual taste. Overall, the layout of the house affords safety, privacy and security for all of the residents without being restrictive or feeling institutional.

Since leaving the congregated setting, there have been many changes to Helen's life. She no longer returns to the campus for a her full day service, but is supported by staff on an individualised basis. This allows her to access activities in the community and specific campus activities such as swimming. Helen enjoys spending time in the comfort of her own home. This model of personalised supports is aligned to the New Directions policy and, chatting with the staff about how Helen will be spending the rest of her day and week, it is evident that considerable thought and planning goes into ensuring that Helen's routine is led by her and remains flexible in response to her needs.

The staff believe that Helen has settled well in her new home. On the day we visit and meet Helen, she is sitting at the table as a staff member chats to her while she finishes a job in the kitchen. She is happy to sit with us for a while as we chat and she responds positively when we talk to her about family.

Helen's family take a very active interest in her life and well being, with frequent visits and regular phone calls. They also link with the service to take Helen home for visits and stays with various family members. It is clear during the visit that the staff recognise the importance of family to all the residents, including Helen, and strive to ensure they fully enable families to be an active part in the life of the people they are supporting.

Overall, moving from the congregated setting has been a positive move for Helen and her family. As she is now supported in her own home, her dietary requirements can also be more easily met which helps to improve the health outcomes for Helen in the long term. Since Helen has been living in her new home there has been a dramatic decrease in the incidence of behaviours that

challenge which suggests that moving to a new environment, coupled with the delivery of person centred supports, are improving Helen's overall sense of well being.

### Mark's successful progression to mainstream education (RT/CDETБ)

Mark is a young man who started his training with the Central Remedial Clinic (CRC) in the Rehabilitative Training Centre (RTC). During his time in RTC, Mark achieved a number of QQI Level 2 & 3 Component Awards. He then progressed on the City of Dublin Education and Training Board (CDETБ) employability skills programme where he achieved a QQI Level 3 Major Award in Employability Skills. Mark also achieved an extra Component Award in Planting and Potting by hand while on the CDETБ programme.

When he started on the CDETБ programme he explained he had a keen interest in sports and the gym. His dream job was to become a fitness trainer.

Working on his progression plan he had identified that he would like to progress on to a fitness or sports course to help him reach his goal of becoming a fitness trainer. He researched a number of courses and finally settled with Colaiste Ide, Level 4 Sports Course. He was very excited at the prospect of entering mainstream education and progressing on to a course he felt could really make his dream job a reality.

He has informed us that he is really enjoying his course and making new friends and loves his physical class with his gym teacher. He is now studying subjects like Communications, Application of Numbers, IT Skills, Human Biology, Career Planning, and Health Related Fitness.

It is great to see a student progress from Rehabilitative Training and a CDETБ within the CRC on to a mainstream college in the community with a long standing reputation such as Colaiste Ide.

### Joe

This is a short description of a transitional period for a service user in the Brothers of Charity Galway Services who moved to his own apartment from Kilcornan Centre. It is written by his Key worker who worked with Joe in Kilcornan and in his new home in a community setting.

Joe is 48 years of age and is originally from Connemara. He is fourth in a family of six and has been a service user within the Brothers of Charity since 1983. Up until 18 months ago the service provided for Joe comprised of communal campus based accommodation which was situated several miles from a main road and was, by any measure, secluded and isolated. His contact with the community outside of the campus was facilitated by staff who accompanied Joe at all times. The final two years that Joe spent living on campus saw him living alone in a bungalow as the other service users had been rehoused within different communities. For those two years Joe interacted with staff who supported him within his bungalow several times each day. During this time it is fair

to say that Joe learned how to maintain cleaning standards within his home. In 2015 Joe moved to within the heart of a local town Athenry and is now surrounded by a thriving local community. Coming with a new set of challenges, Joe chose the décor and furnishings for his apartment and helped to paint it. Building on his growing capacity to make decisions and choices for himself, Joe received concrete and emotional support to independently utilise the local community and its amenities. To begin with, Joe began walking to the local shop with staff supervision and this eventually led to Joe going to the shop and purchasing basic items fully independently which included paying for the items himself. Joe was supported to bring value to the local community when he joined Local Tidy Towns Group. He began by collecting debris from the paving and the endeavour culminated with him being responsible for the upkeep of a section of medieval wall which was used to display flowers in bloom. As his engagement with the community increased Joe bought a mobile phone to facilitate greater connection with the Tidy Towns and this further resulted in much greater contact with his family members. Joe's membership with the Tidy Towns has significantly increased his interactions with the local community. He is recognised as a contributing member of his community.

Joe enjoys much greater control today over most aspects of his life. He has his own way of cooking, cleaning and chooses his own methods of personal care which he completes independently. Moving forward, Joe's biggest desire is to find meaningful employment and be part of a team which involves decision making and responsibility. In many ways this would afford him with the opportunity to fully develop his own sense of identity. Family are very important to Joe and he is now able to have family members stay as guests in his apartment.

Not wanting to portray an easily travelled road, it is worth highlighting some of the barriers which Joe has had to overcome. From a staff point of view, supporting Joe to overcome the negative effects that come with institutionalisation has been significantly challenging. Positive reinforcement and affirmation have greatly enhanced the capacity for staff to help Joe move beyond institutionalised thoughts and behaviours. His many years living in an environment that he had less freedoms still have an influence on Joe. He, at times, asks for permission to make tea in his own apartment and sometimes hides food wrappers for fear of staff finding out that he is eating when he feels like it. From Joe's point of view, although he does not voice it himself, confidence has been a significant barrier. That said, with every new adventure and every new success comes an ever increasing growth of confidence. A further point worth mentioning concerns Joe's privacy within his own home. It has taken a long time for Joe to fully realise that his front door has a lock, for which he has the only key. This stands in stark contrast to the numbered keypad which adorned his on-campus bungalow which was accessible to anyone who knew the code.

From a staff point of view, having worked with Joe for nine years the biggest obstacle for me was letting him do things by himself. I had to keep my hands in my pockets and let him make small mistakes from which I learned that he would not make these mistakes more than two or three times. Balancing risk was another challenge and I can remember the first time he headed off to the shops and I found it hard to let him go out of my eye line and this brought about mixed emotions. As I snuck around the corner from a distance and watched Joe walk through the town

and go into the shop for all of five minutes which felt like twenty five minutes to come out with his few groceries and to greet a stranger with a smile and a “hello” and to go back about his own business to me was the beginning of changing my frame of mind to my work. Joe is a man like myself and deserves a chance to prove himself. You need to introduce Joe to different challenges and with a little help and direction he has found a happy medium and is a valued member of society. We are only beginning and looking forward to new challenges and adventures.

## Nora

Nora lived in the John Paul Centre in Ballybane, Galway from April 2001. Before that she had been going there for respite for six years.

In 2007 Nora moved to her beautiful new home with four other people that she gets on well with and who she was happy to live with. In the John Paul Centre Nora had been living with eight other people in a bungalow. Initially Nora’s family and the staff were concerned about her moving as they felt she was well supported where she lived, and John Paul is in a good location in the city close to amenities. However, after lots of discussions with Nora’s family and staff, everyone agreed that it would be a great opportunity for Nora for very positive outcomes in her life. Nora visited the house before she agreed to move, and she liked the location. It is in a nice residential area, not too built up, and with young families living there. It’s a few miles from Galway City but also near to Claregalway village. Nora knows a lot of work was done to the house as it needed to be renovated and extended to suit her and the other people living with her. Nora got her own bedroom with en suite and with support from her family she was able to decorate it to her own taste. The renovations also took into consideration her own mobility support needs.

Nora was delighted and her family and staff saw that this move to a new house in the community offered lots of new experiences for her which were not available in John Paul Centre. Some of these were ordinary things which other people take for granted, but which were new and exciting for Nora and her housemates. Things like being involved in preparing their own meals, cooking and baking with the lovely smells that go with this. While Nora was very happy in the John Paul Centre, the dinners came in from the central kitchen, so they missed out on going to the shops to buy their food, the preparation, anticipation, and the pleasure of the smell of lovely food cooking. Nora is able to be a part of all of this, to sit down with her housemates and staff to eat their meals, whereas in the John Paul Centre, the staff would have gone to the canteen for their dinners. There is also a lovely back garden where Nora and her housemates attempted, with the support of the staff, to grow some vegetables and nice flowers. They also sit out in the summer time and have barbecues.

It is easier for the staff to plan with Nora and her housemates what they want to do as they are a smaller group. They all like some different things, e.g. music and concerts but also they all like some things that are the same, like swimming. When they moved they and the staff found out what was available to do in and around Claregalway. They found that they could go swimming in the local hotel pool and then go for a nice lunch or tea in the hotel. There are lots of local shops

and plenty of nice walks around the area. They can also go into the city. Nora loves music and going to concerts in and around Galway and the staff support her to go. Nora also sometimes goes for short breaks away in Ireland.

When they first moved they continued to attend a Day Service on John Paul campus, but after a year or two they decided that they wanted to spend more time doing activities in their local community. They gradually reduced the time by just going in for two days per week and doing more activities from home. Now they don’t go into the Day Service at all. Sometimes they access an art and drama programme and they enjoy a very full programme of activities from their own home locally or in the city. They still have to do their physio programmes but that can be fun. Nora always had good and very regular contact with her immediate and extended family and she is fully involved and supported to attend any and all family functions which she really enjoys.

All of the above are part of Nora’s normal everyday life, but her move to the community has changed the mind-set of all those who support her, and their willingness to try new things. Nora is excited and looking forward to lots more exciting times ahead.

## INTRODUCTION

**WHAT?** The *Transforming Lives* Programme is a national collaborative effort to build better services for people with disabilities. It is part of the wider national effort for Building a Better Health Service.

OUR VISION IS:

**“To contribute to the realisation of a society where people with disabilities are supported;**

**(a) to participate to their full potential in economic and social life, and**

**(b) to have access to a range of quality personal social support and services that enhance their quality of life and well-being.”**

OUR OBJECTIVE IS:

**To ensure full inclusion and self determination for people with disabilities.**

**WHY?** We need a co-ordinated effort and programme of work to deliver real changes and improvements that address the needs of people who use our services and the challenges for delivering safe, effective services.

### 1. Better experience for service users:

In the past, Disability Services in Ireland have been centred on group based service delivery. Findings from public consultation clearly show that people are looking for more choice in Disability Services. They are looking for flexible services that meet their individual needs.

We are changing to enable greater control and independence for people with disabilities.

This means implementing better practice policy so that care services can better respond to individual needs. It also means that individuals and families have a say in what supports would best help them live meaningful inclusive lives in their communities.

### 2. Better prepared for increased demand:

Information on demographics shows that there will be an increasing demand for disabilities services in the future. Already today services are struggling to provide sufficient quantity and quality of services. We need to find new ways of working that will ensure more effective and more efficient services, not just for today but for future generations.

We are changing to have more needs-based assessment and better data management systems so we can better meet needs of people who use our services.

This means people working across the sector will have the information they need to make informed decisions to manage services in the best possible way.

### 3. Better transparency and accountability:

Disability Services are provided by multiple agency types and organisations and serve a wide variety of needs.

We are changing to have better capacity for national review and quality assurance of national standards in areas such as governance, funding, quality and outcomes.

This means ensuring people who use services receive consistently safe, quality care across all service delivery and can expect system-wide transparency and accountability.

### WHO?

Supported by a National Programme Office, *Transforming Lives* is being delivered by a National Cross Sector Steering Group and Cross-Sector Working Groups. This involves key members from across the Disability Service sector including representatives from the Health Service Executive, the Department of Environment, the Department of Health, the Department of Public Expenditure and Reform, the National Disability Authority, Inclusion Ireland, the Umbrella Bodies and Parent Representatives. Membership of the Working Groups are noted in this report.

### WHEN?

The scale of work required to realise the longer-term vision requires a multi-year programme of work with a long-term commitment to delivery.

Our approach is action-focused so that we can also deliver tangible short term benefits as we build better services for longer term sustainability.

The Working Groups work on an annual planning basis; agreeing key delivery milestones for the year ahead and reporting on progress and delivery at the end of each year.

This is a Progress Report for all our stakeholders across the sector, to share information about the work being done.

### HOW?

OUR STRATEGIC AIMS:

We are working together as a sector to deliver our strategic aims to:

- [Migrate services to a person-centred support model](#)
- [Establish an administrative and governance framework for transparent and accountable services](#)
- [Achieve optimal efficiency in how we manage services to make best use of limited resources](#)
- [Put in place a commissioning and procurement framework that ensures quality service delivery](#)
- [Develop national standard resource allocation model to support staff by ensuring appropriate capacity and skills mix](#)
- [Establish an information infrastructure to enable better data management and informed decisions](#)
- [Develop strategic and operational plans that ensure service improvements are delivered](#)

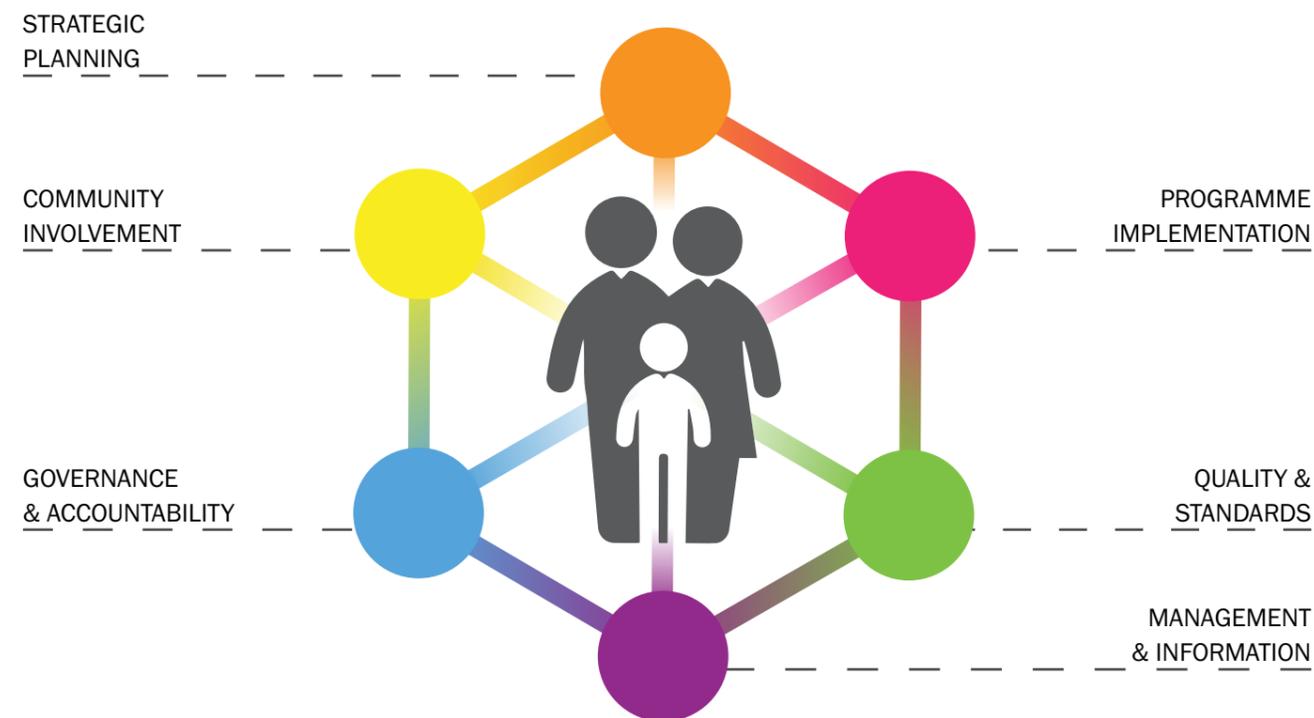
## SIX PRIORITY STRANDS OF ACTIVITY

Delivering our strategic aims requires a joined-up approach to tackle the challenges and deliver co-ordinated actions.

The HSE provides and funds a range of services for people with intellectual, physical and sensory disabilities, autism and their carers. This includes basic health services as well as assessment, rehabilitation, income maintenance, community care and residential care respite, home care and day care. Some services are provided directly by the HSE across the country, whilst many of the community, residential and rehabilitative training services are provided by voluntary organisations with grant aid from the HSE.

We recognise that to best support people with a disability to live full and meaningful lives means we need better joined up thinking nationally across Government Departments which may provide other services and supports such as housing or social services.

The *Transforming Lives* Programme is taking this joined up approach and is being delivered through a National Cross Sector Steering Group and six Cross-Sector Working Groups across six priority strands of activity.

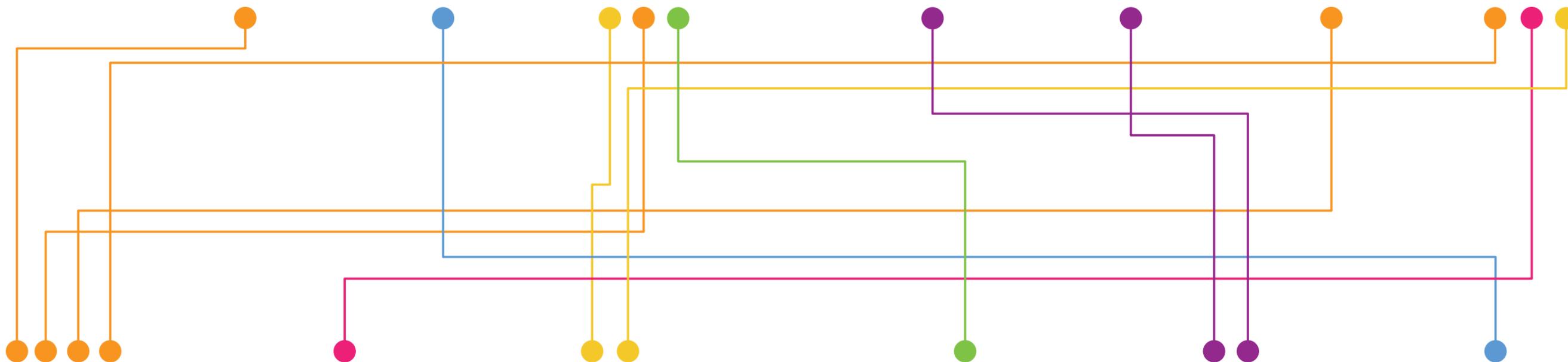


# WORKING GROUPS

## SIX PRIORITY STRANDS OF ACTIVITY

### STRATEGIC AIMS

- Establishment of administrative and governance framework
- Achievement of optimal efficiency
- Implementation of a commissioning and procurement framework
- Development of a resource allocation model
- Establishment of an information infrastructure
- Development of strategic and operational plans
- Migration towards a person-centred support model



### 01 STRATEGIC PLANNING

Being well informed is the basis of good planning. Whether this is learning from services that are already delivering excellence and better practice, or having the right tools, information and data needed to make informed decisions about the future needs of people who use the services.

This strand of activity is about **establishing the national knowledge base** needed to plan and future-proof our services for the years to come. It includes developing a better understanding of future needs as well as piloting new approaches or enabling solutions that have proven effective locally to be implemented nation-wide.

### 02 IMPLEMENTING POLICY

The clear over arching policy objective is to ensure that service planning begins with user needs assessment and that services are designed to support people to participate to their full potential. Policy has been developed for each of the three main category of services; (1) Services for Children and Young People (2) Day Services and (3) Residential Services.

This strand is about **putting policy into practice**, working with services and key stakeholders to enable the actions needed to implement policy objectives. Three sub-groups are established to work across each of the three policy areas.

### 03 COMMUNITY INVOLVEMENT

In order to support people with disabilities to live active engaged lives within mainstream, our services need to be connected to other local community services. We need to develop networks that support this integration at a local level. We also need to ensure an inclusive approach is taken to planning and policy so that persons with a disability and their family members are engaged in the process.

This strand of activity is about maximising **engagement with people who use our services, their families and local communities**.

### 04 QUALITY & STANDARDS

Ensuring quality and standards are consistently met requires a robust structure or ‘framework’ which clearly defines the quality and standards in practical terms for those delivering services and provides effective mechanisms to check and control that these quality and standards are being delivered. Ensuring successful outcomes is an integral part of delivering quality services.

We need **robust national Quality and Outcomes Measurement** for adults and children. This activity strand will develop this framework with clear performance indicators, so that we can measure and monitor that services are being delivered in a way that meets recognised standards of quality and safety.

### 05 MANAGEMENT & INFORMATION

The health services in Ireland are in the early stages of implementing a unique identifier for everyone when using the health services. Supported by improved information management systems this will enable all services to better plan, track and monitor the delivery of care.

This activity strand is concerned with developing **the right tools and technology to capture the right information** and in the same way across Disability Services. For example, using standard person-centred assessment tools to identify individuals’ needs across the sector will best provide the information needed to plan and manage service delivery to meet those needs.

### 06 GOVERNANCE & ACCOUNTABILITY

Good governance and accountability is demonstrated by safe, quality, effective and efficient services that are delivering successful outcomes for the people who use those services. Each of the activity strands are concerned with enabling this to be realised and measured.

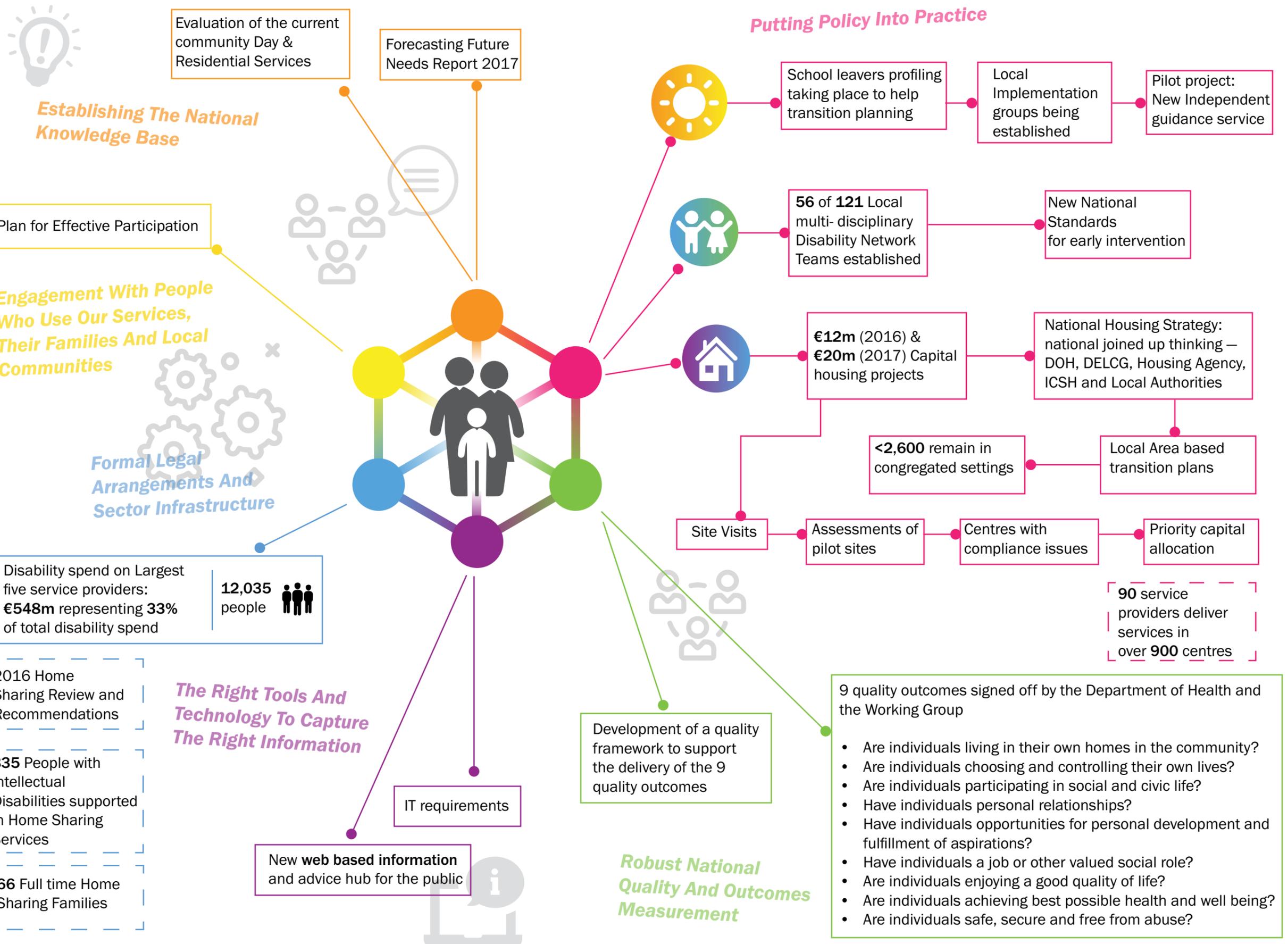
This activity strand is concerned with putting in place the **formal legal arrangements and sector infrastructure** needed to underpin transparency and accountability in Disability Services. Service Arrangements are a priority mechanism to enable this as well as a fit for purpose national shared database and IT system that allows greater controls assurance and more co-ordinated approaches to governance — reducing wasted costs, duplicated work and ineffective data control or information verification.

## What?

The *Transforming Lives* Programme is a national collaborative effort to build better services for people with disabilities. It is part of the wider national effort for Building a Better Health Service.

## Why?

1. Better experience for service users.
2. Better prepared for increased demand.
3. Better transparency and accountability.



# 01 STRATEGIC PLANNING

The snapshot reflects the work of the six working groups during 2016. The key objectives are as follows:

## Working Group 1 – Strategic Planning

- Report on the volume and nature of future needs in Disability Services over next ten years.
- Progress the evaluation of policy Implementation across a number of service providers.

## Working Group 2 – Implementing Policy

- Congregated Settings.
- New Directions.
- Progressing Disability Services for Children and Young People (0-18's).

## Working Group 3 – Community Involvement

- Complete the Development of a Service User Participation Framework.

## Working Group 4 – Quality & Standards

- Develop a National Quality Framework for Disability Services.

## Working Group 5 – Management & Information

- Provide a report on the Information System requirements for Disability Services in Ireland which will be enabled by appropriate IT systems.
- Development of a web based system which will act as a single point of information and advice on the Disability Service provision for service users, family and the community.
- Development of outcome focused key performance indicators on an annual basis.

## Working Group 6 – Governance & Accountability

- Review the Service Arrangement Part 2 schedules on a annual basis.

## NATIONAL WORKING GROUP MEMBERSHIP

Eithne Fitzgerald, (Independent Chair)

Christy Lynch, KARE

Joanne McCarthy, Disability Federation of Ireland

Denise Cooney, Enable Ireland

Dr. Mary T. O'Mahony, Health and Well Being

Representative

James O'Grady, Independent

Jane McEvoy, Saint John of God Services

Anne McGrane, Department of Health

Brian O'Donnell, National Federation of Voluntary Bodies

Grainne Collins, National Disability Authority

Sarah Craig, Health Research Board

Catherine O'Shaughnessy, Health Service Executive

Fionnuala Donohue, Health Service Executive

2016 DELIVERY MILESTONES COMPLETE ✓ Population Needs Assessment  
✓ Existing Service Evaluation Complete

## PROGRESS REPORT

### NATIONAL REPORT FORECASTING DEMAND FOR DISABILITY SERVICES

Building on population needs assessment and existing service evaluation, the Working Group are developing a national report on forecasting future needs. An interim report is available since quarter two 2017. This is timely for incorporating findings from the Census 2016 data. Basic data is available since June and the disability volume and tables will be ready in November. The final National Report Forecasting Demand for Disability Services is planned to be available by the end November 2017.

### NDA EVALUATION OF CONGREGATED SETTINGS ACCELERATED PROGRAMME

The NDA are progressing the evaluation of the Congregated Setting Accelerated Programme. There are 157 individuals in the first phase of the accelerated sites and 98 of these individuals were profiled by end December 2016. It is planned to have the full 157 individuals profiled by the end of Quarter One 2017.

Follow up interviews with individuals who have decongregated to the community will take place at the end of 2017. In preparation for this stage of the evaluation process, two rounds of training of interviewers have been completed.

# 02 IMPLEMENTING POLICY



## NATIONAL WORKING GROUP MEMBERSHIP

Martina Queally, *Health Service Executive (Chair)*  
 Ann Bourke, *Health Service Executive*  
 Suzanne Moloney, *Health Service Executive*  
 Anne Melly, *HSE Dublin North East*  
 Trevor Jacob, *County Wexford Community Workshop (CWCW(E)LTD*  
 Breda Crehan Roche, *Ability West*  
 Arlette Howell, *HSE Dublin North East*  
 Caroline Cantan, *Enable Ireland/HSE*  
 Fidelma Murphy, *Enable Ireland*  
 TJ Duggan, *Cheeverstown*  
 John Scannell, *Department of Health*  
 Donie O’Shea, *National Disability Authority*  
 Joan O’Donnell, *Disability Federation of Ireland*  
 Toni Gleeson, *Disability Federation of Ireland*

Gillian Darrer, *Brothers of Charity*  
 Sinead Stone, *Health Service Executive*  
 Clare Collins, *Department of Health*  
 Kathleen Morris, *Rehab Care*  
 Clare Dempsey, *St. John of God Community Services*  
 Brendan Broderick, *Muiriosa Foundation*  
 Breda O’Neill, *St. Margaret’s Centre*  
 Martina Larkin, *Cheshire Ireland*  
 Sorcha Murray, *Department of Health*  
 Lorraine Dempsey, *Parent Rep*  
 Patricia Curran, *Dept. of Environment*  
 Jim Winters, *Inclusion Ireland*  
 Laura Keane, *Individual Participant*  
 Alison Ryan, *Project Support Office*

## SERVICES FOR CHILDREN AND YOUNG PEOPLE



### KEY POLICY DOCUMENT —“REPORT OF THE REFERENCE GROUP, PROGRESSING DISABILITY SERVICES FOR CHILDREN & YOUNG PEOPLE PROGRAMME” (2009)

*A national policy direction and process to reorganise children’s Disability Services. This process changes the way young people (aged 0–18 years) and their families access and receive health services. It sees the reconfiguration of children’s Disability Services into geographically based Children’s Disability Network Teams. The objective of the programme is to provide one clear referral pathway for all children irrespective of their disability, where they live or the school they attend.*

2016 DELIVERY MILESTONES COMPLETE

- ✓ Children’s Disability Network Teams and Local Implementation Groups (Partially established)
- ✓ 3 bulletins were published and disseminated, providing updates on Progressing Disability Services (PDS), good practice models of service, and information and course running for parents and for staff

PROGRESS REPORT

### DISABILITY NETWORK TEAMS

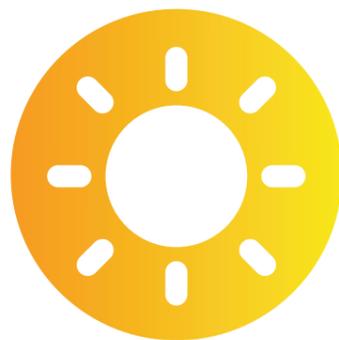
The completion of full reconfiguration to 131 Disability Networks Teams was targeted for 2016. A total of 56 Children’s Disability Network Teams (CDNTs) are in place. No new teams were reconfigured during 2016 due to several challenges. The most significant and common challenges for Local Implementation Groups, leading out on the reconfiguration are noted below along with a progress update on actions underway to tackle the challenges. The remaining 81 teams must be reconfigured by end of 2017.

1. **Accommodation shortfall**  
 Work ongoing with HSE Estates to progress this issue.
2. **Lack of Information Management System (IMS)**  
 Work is ongoing with the national office of the Chief Information Officer, who is fully supportive of the IMS needs for CDNTs and the roll out of the HSE Midwest Management Information System (MIS) (with additions to meet Outcomes For Children And Their Families Framework(OCFF) needs) as an interim measure for those areas with no IMS until the national Disability IT programme is available.
3. **Team Manager—awaiting nationally standardized Grade and Role**  
 The National HR Division is seeking a meeting date with the unions for approval of the draft Standardized Grade and Job Specification for CDN Manager.

KEY POLICY HAS BEEN DEVELOPED FOR EACH OF THE THREE MAIN CATEGORIES OF SERVICES:



SERVICES FOR CHILDREN AND YOUNG PEOPLE



DAY SERVICES



RESIDENTIAL SERVICES

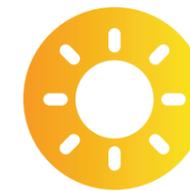


#### COMMUNICATIONS PLANNING – PROGRESSING DISABILITY SERVICES MICROSITE

A new microsite is in development for Progressing Disability Services for Children and Young People. The site will include a range of service information including interviews with parents and staff sharing their experiences of the reorganised children's disability services.

#### ADDITIONAL PROGRESS UPDATES

- **Development posts:** Continue to be monitored
- **Joint Working Protocols (JWP) with Child and Adolescent Mental Health Services (CAMHS) and Primary Care:** Final draft under review by Working Group prior to consultation commencing end of January 2017.
- **National Interagency Agreement Template:** A meeting is scheduled for end January 2017 with Legal Services to progress this piece of work.
- **National Access Policy:** Training is being delivered with Primary Care across Community Healthcare Organisations (CHOs) for Management and for CDNTs or areas soon to reconfigure, where Disability and Primary Care are both ready.



#### DAY SERVICES



#### KEY POLICY DOCUMENT – “NEW DIRECTIONS – REPORT OF THE NATIONAL WORKING GROUP FOR THE REVIEW OF HEALTH SERVICE EXECUTIVE FUNDED ADULT DAY SERVICES” (2012)

*A new approach to Day Services that envisages all supports available in communities will be mobilised so that people with disabilities have the widest choice and options about how to live their lives and how to spend their time. This policy recommends reconfiguring the existing model to deliver more flexible and individualised set of supports. It is underpinned by the principles of person centeredness, community inclusion and active citizenship and quality.*

#### 2016 DELIVERY MILESTONES COMPLETE

- ✓ Day Services Benchmarking Exercise (2015)
- ✓ Interim Standards for New Directions
- ✓ Shared Learning Event to capture the experience of services that had carried out change programmes to align with New Directions
- ✓ Sign off on Data, Occupational Guidance and Rehabilitative Training Reports

#### PROGRESS REPORT

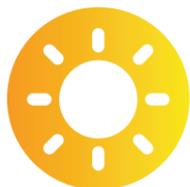
#### INTERIM STANDARDS FOR NEW DIRECTIONS

Interim Standards were developed and an easy read version of the Standards and a communication plan to support the implementation was completed during the year. HIQA approved the proposed approach to the implementation of the Interim Standards.

A self-assessment process combined with a continuous quality improvement planning process has been drafted to provide a framework for reconfiguration and planning that will be implemented in 2017.

#### SHARED LEARNING EVENT

A Learning Event to share experiences of services that had changed to align with the New Directions policy was convened in May 2016. Examples of eleven change programmes were shared and more than 200 people attended. The event was recorded on video and posted on the website to ensure wide distribution of the learning.



#### DELIVERING A PERSON CENTRED FRAMEWORK FOR IMPLEMENTATION

The development of a Person Centred Framework to support the implementation of New Directions was well advanced in 2016 with the completion of the literature review, examinations of current models and engagement with stakeholders. The group leading out on this work has liaised with the wider HSE system and is cognisant of the system wide project that has been developed to develop a person centred culture within the HSE.

#### ESTABLISHING LOCAL IMPLEMENTATION GROUPS (NEW DIRECTIONS)

The establishment of Community Healthcare Organisation (CHO) New Directions Implementation Groups was targeted for completion in 2016. Due to delays in the appointment of key personnel at CHO level, only 2 CHOs managed to establish their Implementation Groups before the end of 2016. A full days briefing was provided to these groups by the National Implementation Group and a support structure is being developed to ensure continuity of approach throughout the country.

#### ADDITIONAL IMPROVEMENTS – REHABILITATION TRAINING, OCCUPATIONAL GUIDANCE & DATA

Additional teams were also established to address the following key areas of recommendation in New Directions: (a) Rehabilitative Training (b) Occupational Guidance and (c) Data. These teams have all completed reports and arising from these reports, the following decisions have been taken:

1. The current Rehabilitative Training programme will be examined and remodelled to best address the transitioning of young people from school to adult day services. This work will be progressed in 2017.
2. Priority data needed to support the implementation of New Directions have been identified and agreed. A resource has now been provided to the national project to progress these priorities.
3. The Report to address the requirement for an Independent Guidance service to support the totality of day services was completed and has been considered by the Working Group. A business plan will be advanced in 2017 to support a pilot of the proposed structure in one CHO.



#### SCHOOL LEAVERS:

In 2016, for the first time, the school leaver process profiled all school leavers. This profiling allows us to better identify and plan, in a consistent way, what supports young people need as they leave school and transition to availing of (HSE funded) adult day services.

The school leaver process also took steps to better support those who provide services to address capacity challenges by releasing early funding. This enabled service providers to rent or lease premises needed to be ready for the September service intake.



## RESIDENTIAL SERVICES



### KEY POLICY DOCUMENT – “TIME TO MOVE ON FROM CONGREGATED SETTINGS, A STRATEGY FOR COMMUNITY INCLUSION” (2011)

*A new model of support in the community by moving people from institutional settings to the community, over a seven year time frame. Individuals will be supported to transition to dispersed forms of housing in ordinary communities, provided mainly by the housing authorities. This policy sees individuals actively supported to live full, inclusive lives at the heart of their family, community and society.*

2016 DELIVERY MILESTONES COMPLETE ✓ Agreement on Future Housing and Support Needs  
 ✓ Shared Learning Events to Demonstrate a Range of Good Practices

### PROGRESS REPORT MONITORING AND REVIEW: YEAR END DATA AND STATUS UPDATE

The year-end data (currently being compiled) identifies that 66 individuals completed their transition in 2016. The number of people currently remaining in congregated settings as at the end of December 2016 is now under 2,600 from an original number of more than 4,000.

Providers had predicted the number of people completing their transition by the end of the year would be higher. However, significant challenges arose. In achieving progress in line with estimated activity levels. These included:

- Finding suitable housing and securing purchase, adaptation, registration etc. before year end;
- Putting in place staff as key “enablers” to support transitions, due to delays in the allocation of Service Reform Funding in 2016;
- Difficulty in meeting ongoing revenue funding costs of transitions (sustainable budget position) alongside pay bill management and HIQA-driven costs.



### Proposed Review of Congregated Settings

A proposal has been developed and forwarded to the Head of Programme for Health Service Improvement to commence a review in 2017 that will examine the configuration of services under the Time to Move On policy. The purpose of this review will be to agree how the policy will be applied in certain specific services, groups of services or for specific residents within a setting. The key principle of this review will be to address the concern that transitioning people into the community in line with the policy recommendations may not be in the best interest of certain individuals or in line with personal wishes or individual choice.

### Site Visits

A total of 12 sites were visited in 2016 focusing on

- Centres with HIQA compliance issues
- Priority Capital Allocation sites
- Pre and post assessment pilot sites.

### CHO TRANSITION PLANS

A requirement of all congregated settings providers and CHOs is that a clear action plan is developed that identifies how the transitions from the congregated settings to community living will be achieved. In February 2016, a Project Action Plan documentation suite was developed and launched as a resource for providers and made available for all providers on-line.

The resource was also shared at a workshop event for the 2016 priority sites and their CHO teams and a number of follow-up steps were put in place to support them in the development and finalisation of these plans in the months after that. The project action plan details the key workstreams that providers need to focus on from an organisational perspective when supporting individuals to transition to the community.

The action plan templates encourage providers to develop their plan around these workstreams and identify specific tasks, targets and milestones. The planning documents also include a number of project management tools that are useful to support providers to track progress and manage issues as they arise. The Project Action Planning Documentation was rolled out to all service providers at the November event. ([www.hse.ie/timetomoveon/](http://www.hse.ie/timetomoveon/))



#### AGREEMENT ON FUTURE HOUSING AND SUPPORT NEEDS

##### Accommodation Requirements

In 2016 guidance was developed for service providers and other stakeholders on the funding options available to provide accommodation and on the good practice processes recommended with regard to how services can support people to determine their housing preferences. The guidance document “Supporting People with Disabilities To Access Appropriate Housing In The Community” was published in May and is available on-line. ([www.hse.ie/timetomoveon/](http://www.hse.ie/timetomoveon/))

Following a Housing in the Community workshop in June, a comprehensive profiling exercise was undertaken to determine how the housing requirement for those in congregated setting will be met. An interim analysis of the returns received to date has provided an insight into the accommodation requirements over the period 2017–2021 under the various funding streams, as well as providing other valuable information in relation to the plans of providers and challenges to be addressed.

This exercise will be completed in Q4 2017 and a Report on Meeting Accommodation Requirements will share the relevant information with the key stakeholders i.e. HSE Estates, Housing Agency, Department Housing Planning Community and Local Government (DHPCLG).

##### THE NATIONAL HOUSING STRATEGY FOR PEOPLE WITH DISABILITIES (NATIONAL STEERING GROUP)

There is ongoing engagement through this group with Department of Health (DOH), Department of the Environment, Community and Local Government (DELCG), Housing Agency, Irish Council for Social Housing (ICSH) and Local Authorities to progress actions under the National Housing Strategy for People with Disabilities (NHSPwD) to promote and maximise use of resources on housing solutions for people transitioning from congregated settings.

In 2016 key issues/work has been:

- Achieving consistent representation and engagement of HSE reps on local groups;
- Examining different approaches of Local Authorities’ to assessment and allocation of resources processes;
- Overseeing the finalisation of local strategic plans and collation into a national plan;



- Revising assessment and allocation documentation;
- Support for improved engagement and development of useful partnerships at local level;
- Identifying challenges to implementation of the NHSPwD and advocating for resources and supports to offset these.

##### HSE CAPITAL AND HOUSING – 2016–2021 PROJECTS PROFILE

There is ongoing engagement with HSE Estates through the Estates Disability Oversight Group in relation to HSE Capital. The purchase of a number of properties will be completed in 2017

##### IMPACT OF 2016 CAPITAL ASSISTANCE SCHEME(CAS) FUNDING REQUIREMENTS

Work has been ongoing with Department Housing Planning Community and Local Government (DHPCLG) and other stakeholders to tease out issues that have arisen in relation to meeting the specific requirements identified in the Capital Assistance Scheme (CAS) Call (Circular 29/2016 and 45/2015).

The Chair of the sub group is liaising with the DHPCLG to establish level of uptake of recent dedicated CAS in order to determine the likely impact of this on the Time to Move On policy implementation in 2017. DHPCLG have indicated this information will be shared with the HSE in January 2017.

During 2017 we will be continuing to work closely with the key stakeholders to address any issues with the new application processes, encourage a strong uptake for the benefit of those in congregated settings and monitor the potentially positive impact of this on policy implementation in 2017.

##### SHARED LEARNING EVENTS TO DEMONSTRATE A RANGE OF GOOD PRACTICES February workshop event for the 2016 priority sites and their CHO teams.

##### June National Event — Housing in the Community Workshop

A workshop on housing took place in June 2016 and the guidance document “*Supporting People with Disabilities To Access Appropriate Housing In The Community*” was launched. ([www.hse.ie/timetomoveon/](http://www.hse.ie/timetomoveon/))

Presentations were made on the day by service users, service providers, approved housing bodies, the HSE, Housing Agency and Department of Housing which provided an opportunity to examine the various aspects



covered in the document and hear about real experiences of how different arrangements were progressed.

#### November National Time To Move On Workshop

In November, the second Time To Move On Learning Event day took place for all congregated settings providers and CHOs. The day focused on the priority accelerated sites as well as:

- Rolling out Project Action Planning Documentation to all providers
- Launching the Communication Plan and key messages documents for Service Providers
- Role of National Advocacy Service
- Developing the Transition Plan and then managing the Transition Process

In addition to this, during the day a number of other topics were also covered in individual sessions. The topics selected were based on the feedback service providers had given as to which areas they would like covered. The areas covered were:

- Experience of communication planning and lessons learnt
- Role of National Advocacy Service
- Developing the Transition Plan and then managing the Transition Process

Several providers presented at the event to share their experience and learning around communication and transitioning.

#### **COMMUNICATIONS PLANNING**

The need for appropriate, pro-active and meaningful engagement with all stakeholders to the implementation of the policy, is well recognised. To support this a high level communication strategy to support the roll out of the policy was completed during 2016. This is made up of two resources documents: *A Key Messages* document and a *Stakeholder Mapping* tool.

These resources have been completed, circulated and made available on-line.

A communication work stream is in place with a small task-focussed group to develop material and resources that will support service communications in line with the high level plan.



#### What this Means for me?

Work has now commenced on the development of “*What this means for me?*” where information sheets and content can be designed for and targeted for specific audiences.

#### Bulletin, Webpage and Email

The first bulletin for Time to Move On was published in July 2016 and coincided with the update of the webpage and launch of a dedicated email address [timetomoveon@hse.ie](mailto:timetomoveon@hse.ie).

# 03 COMMUNITY INVOLVEMENT

## NATIONAL WORKING GROUP MEMBERSHIP

Paddy Connolly, Inclusion Ireland – (Chair)	Mary Walsh, <i>Health Service Executive</i>
Geraldine Graydon, <i>National Parents and Siblings Alliance</i>	Rachel Cassin, <i>Leap</i>
Martin Naughton, <i>Disability Federation of Ireland</i>	Alice Griffin, <i>DESSA</i>
Des Kenny, <i>Retired CEO Voluntary Agency</i>	Gary Lee, <i>Centre for Independent Living</i>
Niall Keane, <i>DeafHear</i>	Bridget Boyle, <i>Irish Wheelchair Association</i>
Mary Stringer, <i>Catholic Institute for Deaf People</i>	Adrian Noonan, <i>Service User</i>
Teresa Dykes, <i>Health Service Executive Sligo</i>	Brian Carroll, <i>Service User</i>
Tony Darmody, <i>Retired CEO Voluntary Agency</i>	

2016 DELIVERY MILESTONES COMPLETE ✓ **Participation Framework**  
 ✓ **Advisory Group in Place**

PROGRESS REPORT The final report “Plan for Effective Participation” has been completed by the group facilitators. The final report (Phase 1) and the implementation plan (Phase 2) will be delivered by mid February 2017.

### IN MEMORIAM



### Martin Naughton

For many decades Martin was a leader and an inspiration to those of us who campaign for equality and human rights for persons with a disability. Martin had a long history of being an innovator and pioneer of new movements or initiatives to advance the right of persons with a disability to have choice and control over the services and supports they receive.

Our thoughts are with Martin’s family, friends and personal assistants and we commit ourselves to continuing his work.

Ar dheis Dé go raibh a anam dílis.

# 04 QUALITY & STANDARDS

## NATIONAL WORKING GROUP MEMBERSHIP

Teresa Mallon, <i>Saint John of God Services (Chair)</i>	Michael O’Connor, <i>Not for Profit Association</i>
Francis Coughlan, <i>SOS Kilkenny</i>	Bernard O’Regan, <i>Western Care</i>
Maura Morgan, <i>Health Service Executive</i>	Ruth O’Reilly, <i>National Disability Authority</i>
Dermot O’Donnell, <i>Disability Federation of Ireland</i>	Barbara O’Connell, <i>Disability Federation of Ireland</i>

2016 DELIVERY MILESTONES COMPLETE ✓ **Quality Outcomes for Framework Agreed**

## PROGRESS REPORT

### QUALITY OUTCOMES

The Department of Health and the Working Group have signed off on the 9 outcomes recommended by the National Disability Authority(NDA) research department. The 9 Quality Outcomes will now underpin the development of a National Quality Framework for Disability Services.

The 9 Quality Outcomes are as follows:

- Are individuals living in their own homes in the community
- Are individuals choosing and controlling their own lives
- Are individuals participating in social and civic life
- Have individuals personal relationships
- Have individuals opportunities for personal development and fulfillment of aspirations
- Have individuals a job or other valued social role
- Are individuals enjoying a good quality of life
- Are individuals achieving best possible health and well being
- Are individuals safe, secure and free from abuse

The Working Group through the NDA have commenced a tender process to research International Quality Frameworks to support the 9 identified outcomes for people with disabilities.

## 05 MANAGEMENT & INFORMATION

### NATIONAL WORKING GROUP MEMBERSHIP

Ger Reaney, <i>Health Service Executive Cork (Chair)</i>	Deborah Jacob, <i>Health Service Executive Finance</i>
Sheila Marshall, <i>Health Service Executive Dublin North</i>	Dharragh Hunt, <i>National Disability Authority</i>
Allen Dunne, <i>Disability Federation of Ireland</i>	Harry Harris, <i>Department of Health</i>
AnneMarie Ward, <i>Health Service Executive Northwest</i>	Clodagh O'Brien, <i>Not for Profit Association</i>
Kevin Carragher, <i>Health Service Executive Cavan/ Monaghan</i>	Sarah Kelly, <i>Kare</i>
Sean Abbott, <i>Cope Foundation</i>	Sean Conneally, <i>Brothers of Charity</i>

2016 DELIVERY MILESTONES COMPLETE

- ✓ IT Requirements
- ✓ Web-Based Information and Advice
- ✓ KPI Outcome Focused Criteria

PROGRESS REPORT IDENTIFY IT REQUIREMENT

The report on Information System for the Disability Services has been finalised and is awaiting final approval by the *Transforming Lives* Steering Group.

WEB-BASED INFORMATION AND ADVICE

The job description for the website Project Co-ordinator has been finalised and it is planned to have the post filled by Q1 2017. The template to gather information on Disability Services has been piloted in a CHO area with a 90% return to date.

KPI OUTCOME FOCUSED CRITERIA

The output of the KPI sub group has been finalised and is awaiting final approval by the *Transforming Lives* Steering Group.

## 06 GOVERNANCE & ACCOUNTABILITY

### NATIONAL WORKING GROUP MEMBERSHIP

Deirdre Scully, <i>Health Service Executive (Chair)</i>	Johanna Cooney, <i>Brothers of Charity</i>
Patricia McCormack, <i>Health Service Executive</i>	Clodagh O'Brien, <i>Not for Profit Association</i>
Margaret O'Donovan, <i>Health Service Executive Cork</i>	John Hannigan, <i>National Federation of Voluntary Bodies</i>
Brendan Broderick, <i>Muiriosa Foundation</i>	Kieran Loughran, <i>Disability Federation of Ireland</i>
John O'Sullivan, <i>Enable Ireland</i>	Suzanne Moloney, <i>Disability Specialist Health Service Executive</i>
Vincent O'Flynn, <i>Carriglea Cairde Services</i>	Joanne McCarthy, <i>Disability Federation of Ireland</i>
David Dunne, <i>Saint Michael's House</i>	Deirdre Carroll, <i>Ministerial Nomination</i>
Grainne Duffy, <i>Department of Health</i>	

2016 DELIVERY MILESTONES COMPLETE

- ✓ A National Shared Database and IT System
- ✓ Governance and Accountability Framework for Service Arrangement
- ✓ Guidance on Strategic Alliance/ Mergers

PROGRESS REPORT

The tasks assigned to this working group have been completed. Work has commenced with Section 39 organisations to examine the feasibility of collaborative partnerships, strategic alliances, shared services and mergers that will support improved governance and accountability within the sector.

# THE PROGRAMME OFFICE

The National Steering Group is responsible for the strategic direction and guidance of the *Transforming Lives* Programme, to steer progress and assess performance management of the implementation process. A dedicated Programme Office and team with appropriate skill-sets, has been established to project manage and carry out the implementation.

The work being delivered through a collaborative approach nationally across six priority strands of activity represents an integrated approach to delivering systemic service improvements and the changes needed to realise quality person-centred supports and services.

*Transforming Lives* is part of the wider Programme for Health Service Improvement. The Programme for Health Service Improvement supports the breadth

of initiatives to build better health services across the system. It provides a key oversight mechanism to ensure joined up thinking and a coherent integrated approach for the delivery of sustainable change.

The Disability Services *Transforming Lives* Programme works with the Programme for Health Service Improvement to ensure appropriate accountability, governance and management arrangements are in place and to enable an integrated structured approach to implementing change and improvements.

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For more information on the *Transforming Lives* Programme to implement the Recommendations of the *Value for Money and Policy Review of Disability Services in Ireland* please contact our national Programme Office.

T: 028 40524  
E: [deirdre.scully@hse.ie](mailto:deirdre.scully@hse.ie)  
[www.HSE.ie/Disability](http://www.HSE.ie/Disability)

For more information on the additional initiatives in Disability Services please contact our national office.

T: 01 635 2928  
E: [disabilityops.socialcare@hse.ie](mailto:disabilityops.socialcare@hse.ie)  
[www.HSE.ie/Disability](http://www.HSE.ie/Disability)

# APPENDIX 1 PROGRAMME STEERING GROUP

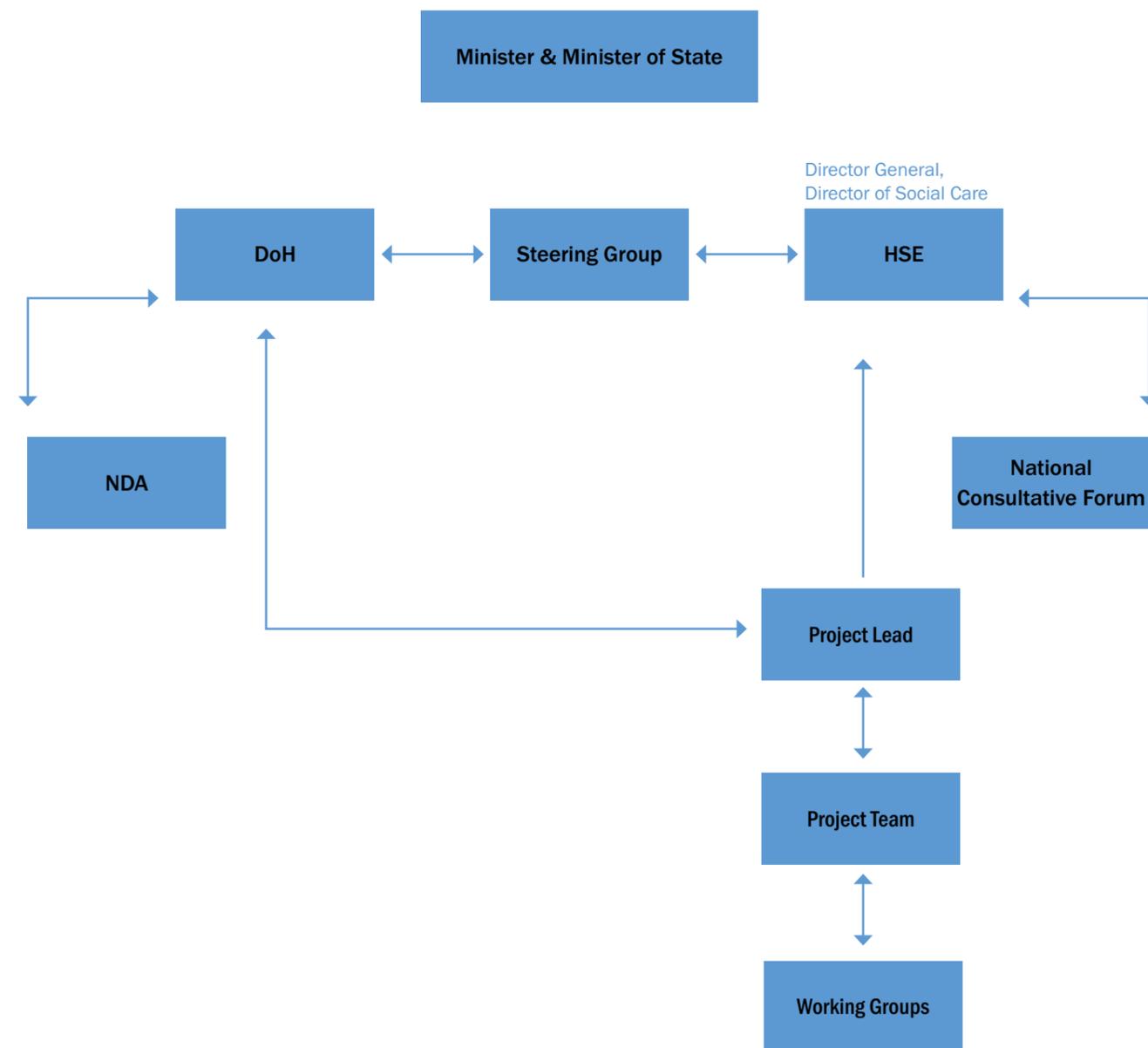
The role of the Steering Group is:

- To oversee the Transforming Lives Programme implementation process.
- To monitor the operation of the implementation framework.
- To agree updates and revisions to the framework as required.
- To monitor the appraisal of the new policy direction.
- To oversee the development of an implementation plan, having regard to the outcome of the policy appraisal.
- To report to the Minister and Minister of State and keep the ministers informed of progress.

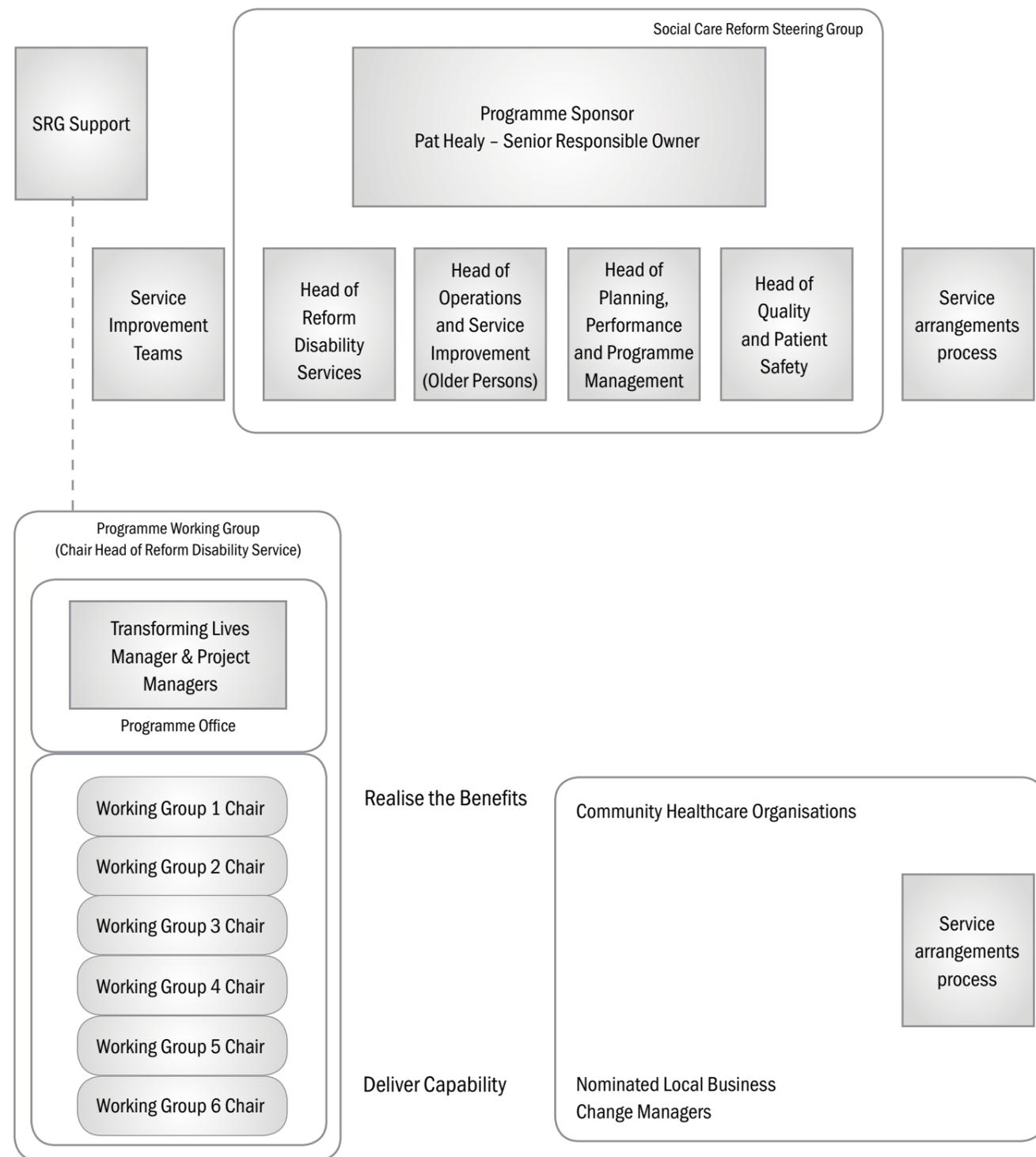
**Membership:**

- Frances Spillane, *Department of Health (Chair)*
- Grainne Duffy, *Department of Health*
- Ann McGrane, *Department of Health*
- Sorcha Murray, *Department of Health*
- Paddy Howard, *Department of Public Expenditure and Reform*
- Pat Healy, *Health Service Executive*
- Marion Meany, *Health Service Executive*
- Deirdre Scully, *Health Service Executive*
- Aideen Hartney, *National Disability Authority*
- Katherine O’Leary, *Inclusion Ireland*
- Clodagh O’Brien, *Not for Profit Association*
- Brian O’Donnell, *National Federation of Voluntary Bodies*
- John Dolan, *Disability Federation of Ireland*
- Joanne McCarthy, *Disability Federation of Ireland*
- Christy Lynch, *KARE*
- Deirdre Carroll, *Ministerial nominee*
- John Scannell, *Department of Health*

# APPENDIX 2 PROGRAMME GOVERNANCE & MANAGEMENT STRUCTURES



# APPENDIX 3 HSE REPORTING STRUCTURE



## ADDITIONAL INITIATIVES IN DISABILITY SERVICES

### PUTTING POLICY INTO PRACTICE

#### GROWING THE CHANGE

The ‘Next Steps’ community of practice promotes and shares learning between organisations developing individualised and self-directed supports, and provides leadership and practical help to organisations as they progress with the movement to individualised services for people with intellectual disabilities. In doing this, the project is identifying drivers and barriers in the change process. The objective of the community is to assist in the wider implementation of national policy for services and supports to people with intellectual disabilities in Ireland whilst supporting individual people in their life journeys. The overall aim of this work is to ensure that people with intellectual disabilities are supported to live a life of their choosing.

The community takes a case study approach to supporting individuals whilst sharing the learning at a national level. Following on from the first two years of case study work in the Next Steps Project, the participating members undertook a reflection on the outcomes to date, published in a report entitled ‘The Journey So Far’ (National Federation of Voluntary Bodies, 2015). In 2016, the community took the learning forward from this report to develop a proposal for the next phase of its work; ‘Growing the Change’. During 2016, the shared values of the community of practice were reviewed, updated and agreed as part of the planning for the next phase of the work. A Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis was carried out on the work of the community and the resulting information contributed to the strategic plan of the Next Steps community. The organisations created individual case study proposals for a range of people they support in response to the continued need for the development of individualised and self-directed supports. At the project level a range of initiatives was planned and begun in 2016, including the development of a self-advocacy tool the ‘Voice Box Video Booth’. This will bring the views of people with intellectual disabilities on topics of concern to them in their daily lives; gather relevant assistive technologies that support people in maximising their independence; and the analysis of areas of practice for which learning inputs will be provided in 2017 to a wide range of stakeholders.

### ENGAGEMENT WITH PEOPLE WHO USE OUR SERVICES, THEIR FAMILIES AND LOCAL COMMUNITIES

#### NATIONAL CONSULTATIVE FORUM

The National Consultative Forum with membership from the Health Service Executive, the Department of Health, the Umbrella Bodies, the National Advocacy Service and Inclusion Ireland was established to provide a platform for meaningful and active management and

participation by service users in the development of policy, practice and organisational strategies.

The forum plays a key role in facilitating dialogue, information sharing and effective engagement with the *Transforming Lives* Programme. As part of the implementation work, the National Consultative Forum will be reviewed with the aim of building on the existing national and local consultative structures so as to develop a model of service user representative and engagement which will support the new model of service delivery.

### ROBUST NATIONAL QUALITY AND OUTCOMES MEASUREMENT

#### NATIONAL STANDARDS FOR RESIDENTIAL SERVICES FOR CHILDREN AND ADULTS WITH DISABILITIES

During 2016 a range of improvements in practice, governance and leadership were undertaken. Existing resources were reconfigured to improve compliance with the National Standards for Residential Services for Children and Adults with Disabilities. This was necessary to address areas of concern highlighted following inspections of residential services by HIQA. While many of the residential services inspected were found to be compliant, a number of inspections highlighted significant challenges that need to be addressed. The standard of care at a number of centres was unacceptably poor and fell far short of the values of caring and compassion espoused by the HSE and the social care sector. The most recent analysis of HIQA compliance for disability residential services indicates a current national compliance rate of 66% based on information received up to November 2016.

#### NATIONAL IMPLEMENTATION TASKFORCE RESIDENTIAL SERVICES

Throughout 2016 the National Implementation Task Force for Residential Services continued to focus on the delivery of a system-wide programme to improve the quality and safety of residential services for people with disabilities. Key areas are outlined as follows

##### **1. Safeguarding Vulnerable Persons at Risk of Abuse**

The Health Service Executive (HSE) is committed to safeguarding people who may be vulnerable and at risk from abuse and launched its safeguarding policy – “*Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures*” in December, 2014. This document provides one overarching policy for services provided directly or funded by the HSE, ensuring;

- A consistent approach to protecting vulnerable people
- A “No Tolerance” approach to any form of abuse and neglect
- A culture which supports this ethos

As part of the implementation of this policy nationwide the following steps have been taken;

- ✓ A National Safeguarding Office has been established, which will ensure implementation of the policy, data collection and the development of training programmes.
- ✓ Nine Safeguarding and Protection teams have been established. Each team, one per CHO, is led by a Principal Social Worker and supported by Social Work Team Leaders and Social Workers.

*Training of staff to date:*

A national safeguarding vulnerable person's awareness programme has been devised for all social care staff. This 3.5 hour standardised programme is delivered currently by 168 approved safeguarding facilitators based in HSE and HSE funded agencies. In 2016 just over 10,000 staff attended the safeguarding training

*The National Safeguarding Committee (NSC)*

The National Safeguarding Committee (NSC), initially known as the National Intersectoral Safeguarding Committee, was established formally in December 2015, arising from one of the actions outlined in the HSE's Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures. This multi-agency Committee, representing the public, private and voluntary sectors, is independently chaired by Ms. Patricia Rickard-Clarke.

## 2. SCD/QID Quality Improvement Programme

The Social Care Division and Quality Improvement Division (SCD/QID) have joined forces in an initiative to deliver support and best practice to HSE run intellectual Disability Services. Throughout 2016 almost 7,000 hours of support was provided to 219 HSE run units in six Community Healthcare Organisations. Workshops took place across the country for Persons in Charge (PIC) and Persons Participating in Managements (PPIM) to support staff in their endeavours to improve compliance with residential standards regulated by HIQA. The Project Toolbox was evaluated and revised at the end of 2016. SCD/QID liaised with a range of stakeholders to collaborate on an integrated training plan for staff of residential services for adults with intellectual disability. Documentation in relation to clinical governance was adapted in 2016 for adult Intellectual Disability residential services.

## 3. McCoy Assurance review

The McCoy Assurance review was published in 2016. The review outlined a Roadmap for Áras Attracta as well as specific recommendations for

Áras Attracta, for the HSE and the disability sector. There were specific recommendations related to Time to Move On from Congregated Settings. All these recommendations are being progressed and the learning disseminated across Disability Services.

### TASK FORCE ON PERSONALISED BUDGETS

Under a Programme for a Partnership Government the Minister for Disabilities established the Taskforce on Personalised Budgets in September 2016. This is a key element of the Government's commitment to give people with disabilities greater control, independence and choice in terms of HSE funded Disability Services. The Task Force meets monthly and a Project Initiation Document and work plan have been signed off. Progress is being reviewed by the Cabinet Committee on Social Policy and Public Service Reform chaired by the Taoiseach. A steering group and a consultative group are in place and all documents relating to the Task Force will be on the Department of Health's website as matters progress.

### ASSISTED DECISION MAKING (CAPACITY) ACT 2015 PERTAINING TO DISABILITY SERVICES IN IRELAND.

The Assisted Decision Making (Capacity) Act was passed by the Oireachtas in December 2015. The Act applies to everyone and has significant implications for health and social care providers in the provision of safe person-centred care. In preparation for commencement of the Act a HSE National Assisted Decision Making Steering Group has been established and has representation from UCC, the Department of Health, Department of Justice, Voluntary Sector, HSE divisional leads and HSE personnel from the quality improvement division. One of the principle roles of the National ADM (Capacity) Steering Group is to develop a code of practice applicable to the health and social care context and to input into the development of other codes through the Decision Support Service (DSS); once established, and the Department of Health. There are four (4) subgroups established under the National Steering Group, namely;

1. Guidance and Documentation
2. Information and Communication
3. Training and Education
4. Advance Healthcare Directives

In addition to the above a HSE Divisional leads forum was established. The responsibility of the Divisional lead for Disability Services is to drive the implementation of the Assisted Decision Making (Capacity) Act 2015. Each Division will be responsible for undertaking an impact assessment of the Act on existing services and practice. This impact assessment

will inform the development of an Implementation Plan for services/staff under their remit including the Section 38 and 39 organisations. Work commence in 2016 on these impact assessments and will continue in 2017.

#### THE RIGHT TOOLS AND TECHNOLOGY TO CAPTURE THE RIGHT INFORMATION

##### SERVICE IMPROVEMENT TEAM

The Service Improvement Team was established by the Social Care Division to support senior staff and teams at local, area and national level in the management of SLA's, service delivery and service indicators. The Service Improvement Team (SIT) provide a bridge with the day to day service delivery at operational level, supporting the implementation of the *Transforming Lives* Programme. The focus of the SIT is to link funding, activity, cost, quality and outcomes of services in current settings and in the context of significant reconfiguration of service. It will enable the maximisation of efficiencies within services, through benchmarking, unit costing of service delivery models and comparison of cost and service models across the sector. The Service Improvement Team has strong linkages with the National Compliance Support Unit, which leads nationally on the Service Arrangement process.

Work is now complete on the review of the five largest organisations representing over 40% of the resource which will provide a strong basis of comparison of unit costs and associated service models which has not been available to the Health Service Executive previously. An update on the largest 5 based on 2016 data is due to be completed in Q1 2017. A review of the next largest 45 organisations progressed in 2016. This provides very valuable information to support change and development of organisations from a HSE perspective national and local and from an organisational perspective.

#### FORMAL LEGAL ARRANGEMENTS AND SECTOR INFRASTRUCTURE

##### HOME SHARING

The HSE established a National Expert Group in 2016 to carry out a review of Home Sharing in Ireland. The report of the National Expert Group; entitled 'Home Sharing in Intellectual Disability Services in Ireland' (HSE, 2016) was published in September 2016.

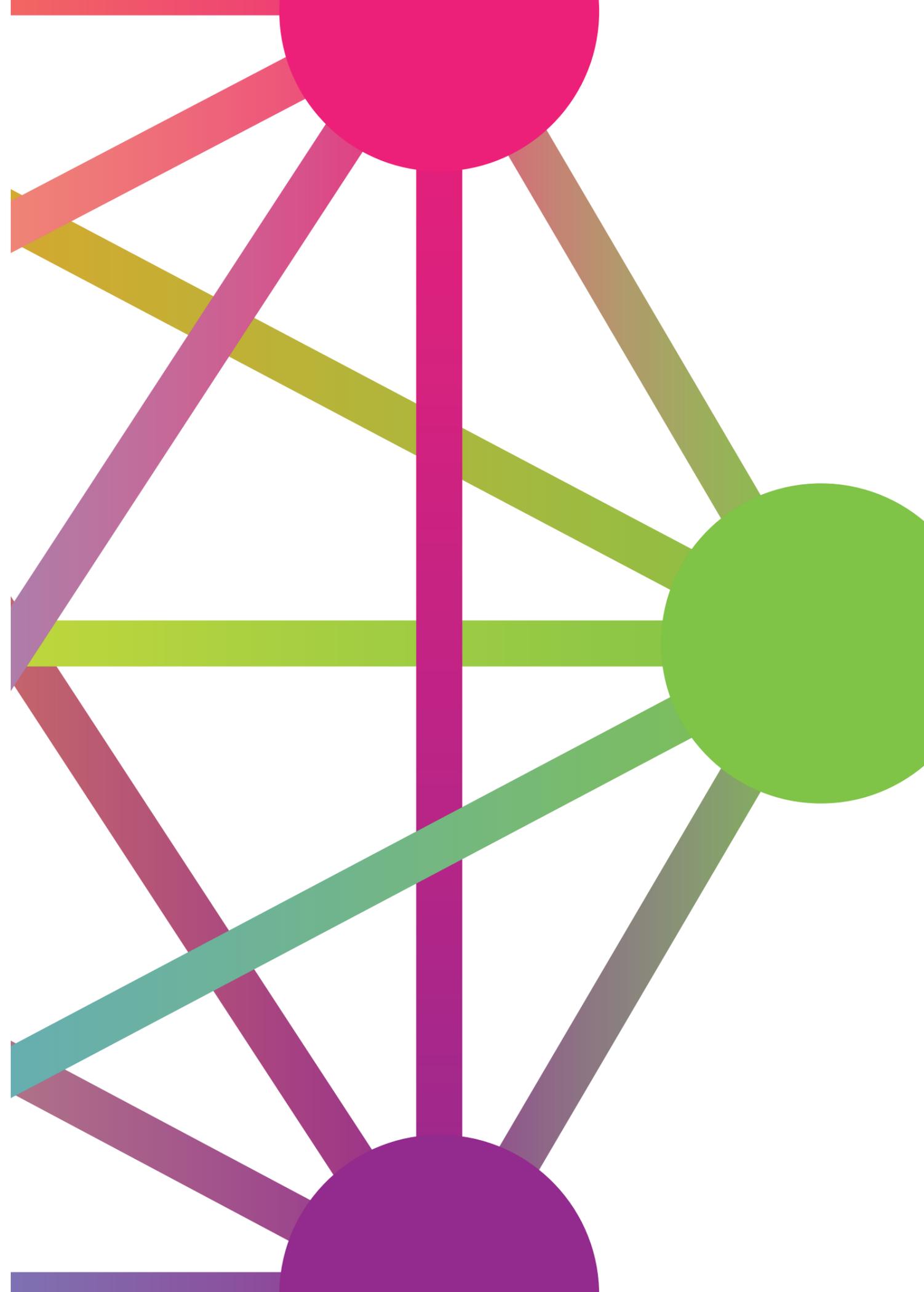
The terms of reference for the National Expert Group incorporated a review of the HSE (2012) document 'Host Family Support Model of Service Provision — Governance/Guidance Document to Support Implementation' and to produce a report with recommendations for the future provision of Home Sharing in Ireland.

The report makes a number of recommendations and calls for the continued development of Home Sharing as a model of service option available to adults and children with intellectual disability. While the

report recognises the many advantages of Home Sharing for people with intellectual disability there are however, strategic and operational challenges in the delivery of this model of support within an Irish context. There are currently 853 people with intellectual disability supported in Home Sharing; 66 of whom are supported full time by Home Sharing families.

The report identifies that there is currently no legal framework for the regulation of Home Sharing in Ireland which is urgently required to underpin the safe governance and management of the service and the HSE and the Department of Health have collaborated on this issue. In addition, an implementation plan to progress the work of the National Expert Group on Home Sharing is being devised and a HSE Disability Specialist has been assigned national lead for Home Sharing.

The National Expert Group advocates for statutory recognition of Home Sharing and for the continued development of Home Sharing as a model of support on offer to people with intellectual disability and their families. The report of the National Expert Group has identified both strategic and operational challenges for Home Sharing within an Irish context while at the same time it has provided the blueprint for resolving these issues.





**Transforming  
Lives**



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive